TESTIMONY OF:

Colleen Wieck, Ph.D.
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on Developmental Disabilities
201 Capitol Square Building
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TO:

Senator John Chafee and the Community and Family Living Amendments Forum Chicago, Illinois

April 12, 1986

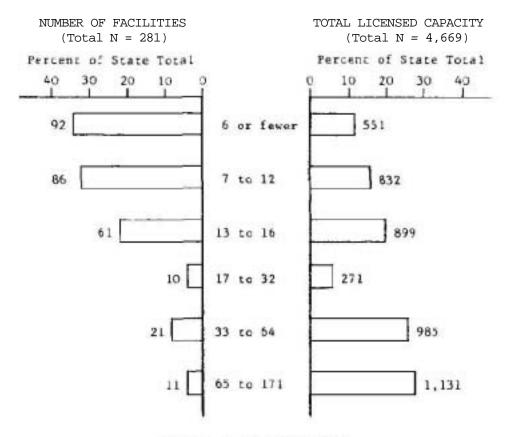
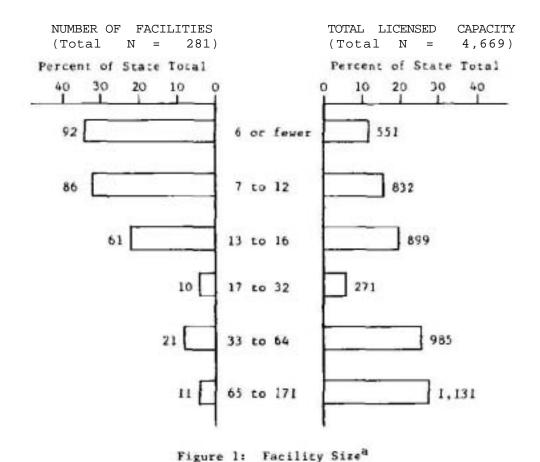


Figure 1: Facility Size



^aDevelopmental Disabilities Program, *Policy Analysis Series Paper No.19: An Update to Policy Analysis Series No. 4 and 15: Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems: 1981* (St. Paul, MN: Developmental Disabilities Program, State Planning Agency, August 14, 1983).

Minnesota Governor's Planning Council on Developmental Disabilities

DEVELOPMENTAL DISABILITIES PROGRAM, STATE PLANNING AGENCY

201 CAPITOL SQUARE BLDG. • 550 CEDAR STREET • ST. PAUL, MN 55101 • 612-296-4018

January 16, 1987

Calleen

To: Sue Abderholden
Anne Henry
Betty Hubbard
Toni Lippert
Ed Skarnulis
Colleen Wilson

FROM: Colleen Wieck, Ph.D.

Executive Director

REGARDING: Medicaid Reform Principles

Here is a copy of the final package discussed by our national counterparts.

I have not had time to prepare a statement of the Minnesota ideas from our last meeting but will do so this weekend.

We'll set up another meeting soon.

CW/amc

Enclosure

Key Provisions	for the states should be authorized to cover such an otherwise eligible person as long as needy his/her income does not exceed 300 percent thorized of the federal SSI payment standard [N.B., utions Unlike Section 1903(f)(4)(c) of the Act, however, coverage should not be linked to the individual's presumed need for institutional care.]	sability An additional income disregard should be included for otherwise eligible workers who require LTC services; this disregard should allow such persons to retain a portion of their earnings for personal use. The disregarded amount should increase as the individual's earnings rise.	The following LTC services for eligible persons with severe disabilities shall tural be reimbursable to the extent that they are covered under a state's Medicaid plan: intermediate care facility services; individual service coordination (case management); individual support services; protective intervention; occupational therapy; physical therapy; diagnostic and assessment services; personal assistance and
Organizing Principles	• The criteria governing income eligibility for the specialized LTC services outlined below should permit coverage of optional categorically needy persons on the same basis as currently authorized for persons in Title XIX-certified institutions and HCB waiver programs.	• A working individual with a qualifying disability should be permitted to retain a reasonable portion of his/her earnings (i.e., as opposed to having them recovered through mandatory contributions to the cost of his/her care).	 The legislation should encourage states to assign high priority to providing services either in the home of the individual's natural or adoptive family or in alternative family or foster living arrangements (i.e., as opposed to congregate care settings). States should be allowed to select from among an array of service options in order to appropriately address the wide ranging needs among members of the target population.
Category	Eligibility (cont.)		Services

TENTATIVE SPECIFICATIONS

Developmental Disabilities Medicaid Reform Legislation

Category	Organizing Principles	Key Provisions
Eligibility	• Medicaid long term care benefits should be limited to otherwise eligible persons with substantial chronic disabilities originating in childhood.	• The eligible population should be defined to include individuals who: (a) meet the state's economic means test; (b) became disabled prior to age 22; and (c) meet the federal SSI test of disability.
	 Persons with disabilities originating in childhood that meet the SSI/Social Security test should be considered presumptively eligible for the specialized LTC services outlined below. Eligibility should be based on the individual's needs rather than on any presumptions about Ms/her level of care requirements or need for a particular residential setting (i.e., a Medicaid-certified LTC institution), as currently required under the HCB waiver program. The legislation should avoid disenfranchising otherwise eligible persons in states with stricter criteria of disability than the federal SSI test (i.e., 209(b) states). In recognition of the fact that a natural or adoptive family generally provides the optimal living environment for children with severe disabilities, federal legislation should remove financial hardships to families caring for such children at home. 	 The legislation should include language mandating LTC coverage of otherwise eligible persons who meet the SSI test of disability but not a stricter state disability criteria. Either deeming of parental income should be waived under specific circumstances or the legislation should establish (or authorize the states to establish) a sliding scale of co-payments applicable to lower to middle income families caring for a child with a severe disability at home.
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Pace Three

	ganizing Principles	Eligible persons who need specialized LTC care; homemaker services; adaptive services should receive an individually tailored service package without having to demonstrate a need for a comprehensive array of services (i.e., services should be "debundled"). Care; homemaker services; adaptive equipment, vehicles and housing; assistive devices; home health services (including prevocational and supported employment services); respite care and other family	Because the cost of room and board transportation; chore services; funding sources (i.e., notably SSI funding sources (i.e., notably SSI payments), such costs should not be considered Medicaid reimbursable services; between the services and residential payments when living persons on the services for persons with severe disabilities should be available on a mandatory basis; others on an optional mandatory basis; under state Medicaid plans. All LTC services for persons with severe disabilities should be furnished in accordance with the provisions of an individualized habilitation plan (IHP). All LTC services for persons with severe disabilities should be furnished in accordance with the provisions of an individual service coordination of the plans. All LTC services for persons with severe disabilities should be furnished in accordance with the provisions of an individual service coordination of the plans. All LTC services for persons with severe disabilities should be furnished in accordance with the provisions of an individualized habilitation plan (IHP). All LTC services for persons with severe disabilities should be furnished in accordance with the provisions of an individualized habilitation plan (IHP). All LTC services for persons with severe disabilities should be furnished in accordance with the provisions of the recipient's IHP, as developed by an individual service coordination of the recipient's IHP, as developed by an individual service services; All LTC services for persons with severe disabilities should be furnished in accordance with the provisions of the recipient's IHP, as developed by an individual service coordination of the provisions of the provisio
	Organizing Pr	Eligible per services sho tailored ser demonstrate of services "debundled")	Because the generally cafunding sour payments), s considered M persons othe benefits, ho receive full in out-of-ho only a reductertain servaisabilities mandatory babasis, underdisabilities accordance windividualiz
Pace Three	Category	Services cont.)	•

Key Provisions	* any inflationary costs exceeding six percent per annum, as measured by the medical care component of the Consumer Price Index. • States which elected not to cover the specialized community LTC services listed above within two	ter gisla ed t Y-bas e (• States should be obligated to outline in a special supplement to their state plans a multi-year strategy for systematically increasing the proportion of total federal-state Medicaid dollars obligated for community-based vs. institutional services.	• A state also should be required to include as a component of its state plan supplement a detailed strategy for expanding community services for eligible persons living at home or in other non-institutional settings.
Organizing Principles			• One general aim of the legislation should be to facilitate the orderly transition of Medicaid dollars from institutional to community-based services.	• Reform legislation also should encourage states to expand community residential, day and support service alternatives for eligible individuals with qualifying disabilities residing at dome or in other non-institutional settings.
Category	State Plan (cont.)			

	Key Provisions	• A state should be required to spell out in Its state plan supplement a selection criteria to assure that all eligible and potentially eligible recipients have equal access to community-based services (i.e., that persons are not assigned lower priority for admission to community-based programs solely because of the extent or nature of their handicapping conditions).	• The legislation should grant states the flexibility to reclassify community-based ICF/MR facilities in an effort to achieve more effective and cost efficient delivery of community services.	• States should be required to describe in their state plan supplement the methods to be used to protect the interests of public employees who are affected by the transfer of persons in institutions to community settings, including arrangements designed to protect the rights and benefits of such employees and provide them with access to appropriate training or retraining programs.
	Organizing Principles	• Access to community-based services should be available to every eligible person, on an equal basis, regardless of the severity of his/her disability or present place of residence.	• The existing institutional bias of Medicaid policy should be eliminated.	• Employees whose jobs are adversely affected by the phase-down or closure of larger Medicaid-certified LTC facilities should be afforded reasonable accommodations.
Page Six	Category	State Plan (cont.)		

Key Provisions	• States should be required to specify in their state plan supplement the policies and procedures that will be used to assure that: a. all personnel have received preservice education and/or training; b. every service agency maintains written personnel policies; and c. in-service training and continuing education services are furnished to service personnel.	• The Secretary should be responsible for developing and field testing competency-based personnel standards.	• States should be required to spell out in their state plan supplement the steps that will be taken to assure that provider agencies have access to needed technical assistance services.	• States should be required to specify in their state plan supplement the methods that will be used to assure that crisis intervention services are available. • States should be required to spell out in their state plan supplements the methods to be used to assure that every eligible person receiving specialized Title
Organizing Principles	• States should be required to develop and maintain an adequate infrastructure to support the expansion and improvement of home and community-based service options for eligible persons receiving specialized LTC services, including the capability of providing staff training, technical assistance, and crisis intervention services.			• Each eligible persons receiving specialized LTC services should have access to individual service Coordination services both within every program in which he/she participates as well as external
Category	State Plan (cont.)			

Key Provisions	XIX-funded LTC services has access to both intra-program and inter- organizational service coordination services. Included should be an explanation of the methods to be used to assure that external service coordinators (or case managers) will be independent of any agency or program providing day and/or residential services to the subject individual.	• Each participating state should be required to specify in its state plan supplement the methods to be used to assure that an appropriate management Information system, which meets the aforementioned specifications, is instituted, including the component parts of such a system and timelines for its implementation. The interested public should have access to all Information and data produced by the MIS as long as it does not violate the confidentiality of individual records.	• Each participating state should be required to specify the procedures to be used in obtaining public input on all relevant features of its plans to expand/improve home and community-based services for persons with severe disabilities.
Organizing Principles	to such programs. The external (or inter- organizational) services coordinator should be administratively independent of all providers of day and/or residential services.	• A state should have a comprehensive management information system capable of: (a) tracking the progress of persons enrolled in Title XIX-funded programs/facilities; (b) identifying the service needs of unserved and inappropriately served persons for potential Title XIX LTC services; and (c) pinpointing systemic flaws or gaps in existing services, statewide, based on aggregated data.	• The regular Medicaid state plan amendment process should be used by states in electing mandatory/ optional LTC service coverages for persons with qualifying disabilities. However, the process of arriving at such determinations, and assuring adequate safeguards and protections, should provide an opportunity for public input.
Category	State Plan		

Key Provisions	should • The legislation should obligate the state to offer eligible persons and their families due process safeguards. • Any party injured or adversely affected by a violation of the Act should have a private right to seek	injunctive relief in federal court (including the recovery of attorneys' fees under specified circumstances).	plicit • HHS should retain its existing statutory authority to promulgate and monitor compliance with SNF, ICF and ICF/MR standards, including conducting federal validation, or "look behind", surveys. [N.B., However, as noted above, the states should be allowed to reclassify community ICF/MR facilities as vendors of other types of Medicaid- reimbursable services and, thus, subject to state community services regulations.] a be shared to play a categories of community day, ito play a categories of community day, residential and support services. a leading lor monitoring compliance and assuring enforcement, should be sub- ject to review and approval by HMS as process.	
Organizing Principles	• Eligible persons and their families s be afforded due process safeguards, including the right to appeal program placement decisions.		• The legislation should include explicit requirements governing the development and enforcement of program standards to assure that all persons participating in Title XIX-funded programs receive appropriate, high quality services. The vulnerability of the target population to abuse and neglect makes it particularly important that states establish adequate procedures for controlling program quality. Responsibility for establishing and enforcing program standards should be shared by federal and state governments, with the federal government continuing to play a major role in setting and overseeing the enforcement of long term care facility standards and the states playing a leading role in establishing and monitoring compliance with community service standards.	
Category	State Plan (cont.)		Quality Assurance	

Category	Organizing Principles	5.' ''
		essential elements that must be included in state standards governing various types of community services funded under this authority (i.e.,
		states should be free to use existing or newly developed standards provided, at a minimum, such standards address certain essential areas specified In
		Secretary of Health and Human Services to complete periodic assessments of
		the adequacy of licensing, monitoring, enforcement and other quality
		assurance components in each participating state.
	and carrying out cogram, increased em	 Each participating state should be required to describe, in its state
	Ψ÷	plan supplement, the component parts of a comprehensive, integrated
	receiving assi	1 7
	party monitoring and objective, valid and	Εì
	reliable methods for assessing such dimensions as the individual's	<pre>monitoring, environmental assess- ments, individual service</pre>
	tal progr ity and s	<pre>coordination (case management), individual IHP reviews/monitoring, individual assessments of</pre>
		tal progress, ndividual int
		and/or parent/advocate monitoring.

Key Provisions	• The Secretary of Health and Human Services should be required to support the development, field testing and dissemination of reliable and valid instruments to assess service outcomes, including outcomes in such non-traditional areas as community integration, individual/family satisfaction, environmental impacts, etc.	• "Individual service coordination" (or case management) services should he defined in the legislation to include two levels of activity: a) intra-program coordination; and (b) inter- organizational coordination. The external (or interorganizational) service coordinator should be administratively independent of any provider of day or residential service to the recipient (see also State Plan).	• An "individual habilitation plan" is a written plan of intervention developed by an appropriately constituted interdisciplinary team which contains specific objectives for achieving the affected individual's service needs, as identified by the results of a comprehensive assessment. Each service objective must be stated in behavioral terms that provide measurable indices of performance, have a
Organizing Principles		• Certain key terms should be defined in the legislation, including "individual service coordination", "individual habilitation plan", "habilitation services", "protective intervention services" and "community living facility".	
Category	Quality Assurance (cont.)		

Category	Organizing Principles	Key Provisions
Definitions (cont.)		projected completion date, be assigned a priority and describe the program strategies to be employed to achieve the desired results. • "Habilitation services" should be defined in the same way as it is defined in Section 9502(a) of COBRA (i.e., to include educational, prevocational and supported employment services not otherwise available to the client through state/local education and vocational rehabilitation agencies). [N.B., Unlike Section 9502(a), application of the revised definition should not be limited to persons previously institutionalized.]
		• An agency(ies) providing protective intervention services should meet the following minimum criteria: (a) it should have access to all programs/facilities 24 hours a day; (b) it should be independent of any agency responsible for delivering or overseeing the delivery of services; and {c) it should have the legal capacity to intervene on behalf of both both children and adults with qualifying disabilities.

Page Thirteen

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Category	Organizing Frincipies	key Provisions
Definitions (cont.)		• The definition of a "community living facility" should be identical to the one used in CFLA (S. 873), including the size limitation (i.e., no more than 3X the average family household size in the area).
		• Existing large group homes (10-15 beds) and "cluster facilities", as defined in S. 873, should be grandfathered into the definition of a "community living facility".
Federal and State Administration	• Any revised legislation should clarify and streamline administrative responsibility for managing Medicaid LTC services for eligible persons with developmental disabilities, at both the federal and state level.	• The legislation should direct the Secretary to establish a separate Bureau of Developmental Disabilities Services within HCFA and consolidate in this new bureau planning, policymaking and operational responsibility for over-seeing the management of Medicaid-funded LTC services for eligible persons with developmental disabilities. • The legislation should explicitly authorize the Governor of each state to assign responsibility for specified management functions related to serving eligible persons with developmental disabilities to different agencies of state government [N.B., the existing single state Medicaid

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Key Provisions	agency would remain; the primary difference is that the Governor (or the state legislature) would have explicit authority to tailor DD-specific agency assignments to local circumstances].	January 9, 1987
Organizing Principles		
Category	Federal and State Administra tion (cont.)	

Consortium for Citizens with Developmental Disabilities

CCDD Medicaid Long Term Care Task Force Contact: R. Gettings, NASMRPD,113 Oronoco St., Alexandria, VA 22314 (703) 683-4202

MEMORANDUM

January 9, 1987

TO: Members, CCDD Medicaid Long Term Care Task Force

FROM: Bob Gettings, Co-Chair

SUBJECT: January 27 Meeting

The CCDD Task Force on Medicaid Long Term Care Services will hold its first meeting of 1987 on Tuesday, January 27 at 9:30 a.m. in the ARC/US Conference Room. The principal topics of discussion will be:

- the Task Force's working agenda for 1987. Please bring with you any suggestions regarding legislative and administrative issues which the Task Force should address over the next twelve months.
- Medicaid Long Term Care Reform Legislation. As I mentioned at the Annual CCDD Meeting last Thursday, an ad hoc group of representatives from ARC/US, NAPAS, NASMRPD, NADDC, TASH and UCPA have developed a series of legislative specifications which, we hope, will serve as the basis for the preparation and introduction of a revised Medicaid reform bill during the 100th Congress. Your copy of these "tentative specifications" is attached. We ask that you review it carefully and come to the January 27 meeting prepared to discuss its contents, as well as future Task Force strategy with respect to such legislation. Keep in mind as you read this document that, at this point, the specifications: (a) have not been formally endorsed by any of the organizations which participated in the development of the document; and (b) are only intended to be the basic building blocks of a bill and not a detailed legislative proposal.

Look forward to seeing you in a couple of weeks.

Attachment

Senator Chafee and Forum participants.

The Minnesota Governor's Planning Council on Developmental Disabilities supports the Community and Family Living Amendments and has supported the bill since 1984. We provided written testimony to your Senate hearing which was held on August 13, 1984, in Minneapolis that outlined the values, issues, and philosophical reasons for our support. We stated at that time:

- 1. CFLA supported a consumer driven system rather than a provider driven system.
- CFLA would help meet demands for service through a range of alternative living arrangements.
- 3. CFLA would emphasize meeting the needs of in dividual residents in small, homelike residential programs.
- 4. COLA would provide less costly alternatives to out-of-home placements.
- CFLA would emphasize and strengthen support services such as day programs and case management.
- 6. CFLA defines the target population in comparable terms with our state statutes, but more attention is needed for emotionally disturbed children and people with mental illness.

Rather than repeating our original testimony, the Council directed me to testify about the results of a nine-month study of our state hospital system. We are interested in discussing the broad range of issues that each state must face in downsizing residential facilities.

During the 1984 Legislative Session, the D.D, Council of the State Planning Agency was given lead responsibility to conduct a study and propose a plan for state hospitals. There were four events that prompted the legislation: (1) the sudden closure of Rochester State Hospital, (2) the Title XIX Home and Community Based Waiver which called for additional reductions in the mental retardation units, (3) the Welsch v. Levine Consent Decree, and (4) the December 1983 proposed reorganization of the state hospital system by the Department of Human Services.

We completed eight separate reports which you have in front of you. Each of these reports answers specific questions

posed by the legislation. In addition to these reports, we published this 40-page graphically illustrated report giving "highlights" of the reports.

An interagency board was established and consisted of 11 state agency commissioners. The interagency board entitled, the Institutional Care and Economic Impact Planning Board, met six times to carry out its mission. This board approved all reports and recommendations that were presented to the Legislature.

Let me emphasize that Minnesota has plenty of plans, and some would argue that our state hospital system is overstudied. The problems with planning is that when major stakeholders are not involved, the planning is meaningless. Second, the Legislature can act without planning or can require planning and then not act. The study that we conducted involved all stakeholders and did result in legislative action.

The first priority in planning must be the individuals who are served; however, other issues need attention such as economic impact, employee displacement, and alternative use of buildings. My testimony will describe how we organized these studies and the conclusions we reached.

PAPER NO, 1: MINNESOTA STATE HOSPITAL FACILITIES AMD ALTERNATIVE USE (BUILDINGS)

The major focus of this study was an analysis of the general condition of the buildings and potential alternative uses of those buildings.

We examined several variables including the years the buildings were built, property size, building square footage, physical condition, plumbing condition, and electrical condition of the buildings.

There are many buildings in the state hospital system which are unused and in poor repair. Many of these buildings continue to be heated because they have not been declared surplus property. There are tables on the disposition of surplus property from 1983-1984 in this report, and our analysis shows that the state does not excel at disposing surplus property.

Even though the projection for services for mentally ill people and chemically dependent people remains constant for the next biennium, the projected decline of people who are developmentally disabled will reduce the current need for building space.

There has been considerable experience across the United States concerning the conversion and disposal of state

hospital properties. We conducted a national survey of states with 43 of 50 states responding.

Generally speaking, state agencies report that they do not save money by using state hospitals for other government uses rather than renting or building other facilities. This is due in large part to the condition and age of the buildings, energy costs, and renovation costs.

Of the 31 institutions reported closed nationwide, none have been purchased by private industry. Over half have been converted to other types of institutions, e.g., corrections, Veteran's, geriatric apartments, college, and religious organization.

Recommendations:

- We recommended a systemwide capital improvement planning process that recognizes longterm space requirements and the condition of the buildings.
- 2. We recommended that unused buildings in poor condition should be declared surplus and demolished if necessary.
- 3. We recommended an aggressive, coordinated marketing strategy should be undertaken for all potential alternative uses of state hospitals. Specific use decisions will require the active involvement of state, county, and local agencies, and affected communities, The uses should not conflict with established state policy and should be compatible with the purpose of state hospitals.
- 4. We supported proposed changes in state law easing constraints on the sale of state property to the private sector.

PAPER NO. 2: MINNESOTA STATE HOSPITAL ENERGY USE AMD COST

Energy consumption in buildings is affected by many factors including original construction features, efficiency of heating plant, severity of weather and type of heating fuel used. Meaningful comparison of energy use at the eight state hospitals is difficult.

The Legislature directed us to analyze the energy efficiency of all state hospital buildings. The analysis was accomplished in five different ways:

1. Energy use by resident/patient;

- 2. Energy cost per resident/patient (FY '83 in 1982 dollars);
- 3. Energy use by square foot/degree day/MMBTU;
- 4. Energy use and cost by square foot of building space (FY '83); and
- Energy coat as a percentage of operating cost.

Recommendations:

We recommended that energy conservation measures continue to be taken:

- 1. utilization of shared savings contracts;
- 2. use of alternative fuels;
- 3. Purchase of electricity from wholesalers;
- separate metering of leased or rented buildings to the tenants;
- 5. Surplus buildings to be identified for demolition to eliminate heating costs; and
- 6. Energy improvements such as a summer boiler.

PAPER NO. 3; A PROFILE OF MINNESOTA STATE HOSPITAL EMPLOYEES

The legislation authorizing the study was very concerned about the effects on the employees should a state hospital close. The legislation sought specific information about the employees: what is the projected displacement of state hospital employees because of deinstitutionalization, and what is the extent to which displacement can be mitigated through attrition, retirement, retraining, and transfer?

There are over 5,900 people, including part-time and intermittent employees working at our eight state hospitals.

- 1. 64 percent of all employees are female; the majority are covered by the Non-Professional Health Care unit, which is the largest bar gaining unit, and this group of employees earn an average wage of \$8.51 per hour.
- 2. The average length of service for all employees is 8.15 years.
- 3. The separation rate for all employees (all forms of termination: death, voluntary, and involuntary retirements) varied greatly in the state hospital system. The total number of separations for FY '84 was 820.
- 4. Under the Rule of 85 (if a person's age and years of experience equals 85), 369 employees are currently eligible for retirement. If

the Rule of 85 were extended, 742 additional employees would be eligible within five years.

The State Planning Agency conducted a survey of state hospital employees to determine future career choices. There were 26 questions, and 3,154 employees responded to the questionnaire.

Here are some results;

Question: "If this state hospital were to close within the next five (5) years, or if patient/ resident reductions were to result in staff reductions, and if I were offered a transfer to another state hospital for a similar position, I would most likely" The hypothetical question was followed by a set of four (4) choices!

- 1. Maintain my current residence, refuse the transfer, and seek other employment elsewhere. 34%
- 2. Refuse the transfer, seek other employment outside the area, and change my address accordingly. 12%
- 3. Accept the transfer and move to the area offered. 24%
- 4. Accept the transfer but would attempt to maintain my current residence and commute if at all possible. 27%
- 5. Unknown. 2%

Question: "If this state hospital were to close within the next five (5) years, or if patient/ resident reductions were to result in staff reductions, and if I chose not to accept a transfer to another state hospital, my next career preference would be "

- 1. Work for a state agency in the field of human services.
- 2. Work for a state agency outside the field of human services.
- 3. Work in another public sector (city, county, federal) in the field of human services.
- 4. Work in another public sector (city, county, federal) outside the field of human services.

31%

Work in private industry in the field of human services. 12% 6. Work in private industry outside the field of human services. 7. Retire, if possible. 7% Self-employment. 8. 14% 9. Return to school. 5% 10. Unknown. 11% Question: "should you wish to continue in the human

services field, what would be your most preferred work setting?" The choices on the questionnaire were:

1.	State hospital.	54%
2.	Privately operated community program (day or residential).	11%
3.	State-operated community program (day or residential).	22%
4.	County-operated community program (day or residential).	7%
5.	Unknown.	6%

We also examined the question of portability of pensions. Pensions are portable in some cases but cannot be transferred when leaving public service.

Recommendations:

- We recommended that any staff reductions resulting from declining state hospital populations should occur through natural attrition and retirement whenever possible,
- The Department of Human Services and the Department of Employee Relations should develop a plan to facilitate the voluntary transfer and retraining (i.e., retraining of workers transferring to mental illness units).

PAPER NO. 4: THE ECONOMIC IMPACT OF MINNESOTA STATE HOSPITALS

A large industry such as a state hospital contributes significantly to a community's economy. The smaller the community

and less diverse its commercial or industrial base, the greater the impact of any closure or downsizing. Economic impact is not only a function of where employees live and spend their money but also where they work in terms of commuting distance.

For purposes of the report, there are three economic impact areas. We used zip codes to define the areas:

- 1. Primary impact zone is where 50 percent of the employees live. (Zip codes closest to state hospital.)
- 2. The secondary impact zone is where 75% of the employees live (includes the primary impact zone).
- 3. The regional impact area is where at least 90 percent of the employees live and includes both primary and secondary zones.
- 4. This report has several sections:
 - a. Direct Effect of Hospital Employment:
 - employment as a percentage of total area employment;
 - hospital payroll as a percent age of total area wage and salary income; and
 - estimates of unemployment by county.
 - b. Indirect Employment Loss.
 - c. State Hospital purchases,
 - d. Effect of Resident/Patient Spending.
 - e. Effect of Visitor Spending.
- 5. Counties where most state hospital employees reside are:

a.	Rice	1,017
b.	Crow Wing	647
c.	Otter Tail	637
d.	Kandiyohi	605.

6. Alternative employment would be more difficult in an area of high unemployment. State hospital counties' unemployment rates as of July 1984 showed a high in Carlton County(Moose Lake) of 10.1 percent, 8.0 percent

in Crow Wing (Brainerd), and 7.9 percent in Otter Tail (Fergus Falls).

- 7. Salaries of state hospital employees may be the most significant factor in community economic impact. Of the total operating expenditures, \$128,433,135, or 85.9 percent, are for personnel coats. The amounts ranged from \$9,809,295 at Anoka State Hospital to \$24,993,232 at Faribault.
- 8. Since the state of Minnesota has a centralized procurement system based in St. Paul, the local state hospital purchases as a percentage of local retail sales are small as shown by the tables on pages 20-26,

Recommendations:

We recommended that alternative economic development strategies can be developed but require a cooperative effort between state and local officials. Economic impact zones may be one way to handle this issue in the future.

PAPER NO. 5: PUBLIC OPINIONS ABOUT STATE HOSPITALS

A significant part of the study of the state hospital system was the development of a public process which provided Minnesotans with an opportunity to express ideas and concerns regarding the future of state hospitals and the delivery of services to persons with mental illness, mental retardation, and chemical dependency.

This public process involved three major elements:

- The convening of nine town meetings, one in each area of the state served by a state hospital and one in the Metro area. (Over 5,000 people attended. There were 362 witnesses, and 80 separate organizations were represented,)
- Soliciting letters from the public and interested parties who would express their views.
 (Over 433 letters were received.)

a.	Pro state hospital	117
b.	Neutral	15
c.	Pro community-based facilities	121
d.	Opposed the waiver	49
e.	Against state-operated communit	У
	facilities	131.

- 3. Receiving calls during a "toll-free call-in" day. A total of 202 calls; 174 favored state hospitals.
- 4. We also sent a "Dear Colleague" mailing once a month to 1,500 people giving results and announcing meetings.

The overwhelming message of the town meetings and phone calls was to keep the state hospitals open. The letters were split on this issue.

Here are the major themes that we heard at the town meetings:

Concerns about patients and Residents:

- The special needs of residents should be the primary concern in planning the future of state hospitals.
- Persons most "difficult to place" because of severe behavioral, physical, medical, communication, or multiple handicap problems are served by state hospitals.
- Residents and patients need quality care and a base of support-state hospitals are the only home they have, they should not be made "home less" nor "shuffled about,"
- The improvement of residents and patients has been documented, individuals described the progress they have made. Some families prefer the state hospital placement.
- The fact that state hospitals are geographically dispersed makes it easier for families to visit. Closure is viewed as forcing families to travel longer distances.
- During the call-in day, several callers cited incidents and criticized both state hospitals and community services because of inadequate or inappropriate treatment.
- Family members requested greater involvement and respect from staff.

Views on Community Programs:

• Individuals have moved out of institutions and into the community. They have improved.

- Community programs [community mental health centers, case management, and community support programs) need more financial support.
- Community placement will occur, but it must be orderly.
- Community-based services are client-centered and provide integration.
- Residents have a right to live in the community. The state hospital is not the least restrictive environment.
- The state should phase out of operating any program. The state should use a "request for proposal" approach. The state cannot provide services and at the same time monitor itself.
- We need a state policy on deinstitutionalization.
- Do not stop community-based facility development because of employees and economic impact issues.
- Community services are not available in all parts of the state.
- Some community services experience high staff turnover. Staff aren't well trained. Community services are underfunded. Community programs do not provide a full range of therapy and health care services. Class action suits may be necessary to address inappropriate placements in the community.
- Community-based facilities do not accept all types of people.
- Community programs do not provide the same level of care as state hospitals.
- There is abuse in the community programs and overmedication in some.
- Community facilities are not prepared for the clients who are leaving state hospitals.
 - · County case management is understaffed.
- Some state hospital programs are smaller than larger group homes.

Quality of State Hospital Staff and Care:

- State hospital staff and the care provided were described as caring, helpful, dedicated, the beet, concerned, enthusiastic, skilled, superior care, excellent care, warm, professional, and nationally recognized.
- Staff care about residents and provide a surrogate family relationship 24 hours per day.
- Staff are concerned about quality of care, continuity of care, standards, and a multidisciplinary approach.
- state hospital staff salaries are justified be cause the residents are the most difficult to serve. The salary levels in the community are low by comparison.
- Staff turnover rates are lower in state hospitals compared to community services.

Community Economic Impact on Hospital Closure

- The effect will be an economic chain reaction characterized by direct lose of hospital jobs, indirect loss of jobs because of slowed industrial growth, lowered gross community income, reduced retail sales, closed stores, fewer families, underutilized schools, increased taxes, higher utility costs, depressed housing market, and rising unemployment.
- Several attempts to estimate the magnitude of the economic impact were presented.

A summary of every town meeting is provided in this policy paper. A file of letters is also available and copies of transcripts from the meetings.

PAPER NO. 6: RESIDENTS/PATIENTS

Minnesota's state hospitals exist to serve people with mental illness, developmental disabilities, and chemical dependency. while there are many factors which will influence the future of state hospitals, a very important factor must be the individuals for whom they exist.

All eight state hospitals do not provide the same services. Cambridge and Faribault state hospital serve only persons with developmental disabilities; Anoka serves only persons with mental illness and/or chemical dependency.

The state hospital study also found:

- 1. In 1960, a peak of 16,355 residents/patients were served in the state hospital system.
- 2. In FY '84, the average daily population of the state hospitals was 4,006 people: 1,230 people who were mentally ill; 2,182 people who were developmentally disabled; and 594 people who were chemically dependent.
- 3. Patients who were mentally ill range from the severest forms of illness (9 percent) to the least severe symptoms (12 percent). Patients who experienced psychotic episodes, attempted suicide, and abused drugs comprised 26 percent of the state hospital population; and patients with poor social skills, little initiative, and difficulty controlling emotional control comprised 39 percent of the population. The remaining 13 percent have limited social interaction and self-care skills.
- 4. 90 percent of the residents in state hospitals were severely or profoundly mentally retarded.
- Residents who were developmentally disabled were highly dependent in areas such as selfpreservation (ability to egress a building on their own in case of an emergency), behavior problems, bathing, grooming, and dressing,
- 6. Patients with chemical dependency were typically young white males who were single, un employed, had a high school degree or less, were alcohol dependent, and were indigent.

Recommendations:

The study of "Patients and Residents in Minnesota State Hospitals" provides only preliminary information about demographic characteristics. The Institutional Care and Economic impact Planning Board recommended that additional reports be prepared and recommendations regarding the relationship between state and county responsibilities be submitted to the Legislature. The board also recommended increased emphasis be placed on supporting quality of care and quality of life in the current service system.

PAPER NO. 7: THE COST OF MINNESOTA STATE HOSPITALS

The legislation mandating the state hospital study and plan required the Long Term Health Care Commission to "evaluate the comparative costs to the state institutional and noninstitutional care for developmentally disabled persons." There are four parts to the cost report: (1) review of literature, (2) revenue and expenditures of state hospitals, (3) comparisons of money spent on institutional and community facilities, and (4) a needs approach to cost. Here are some highlights from the cost study:

Costs of State Hospitals:

- 1. Fifteen (15) years ago, the care given in state hospitals was custodial, and the cost per day was extremely low,
- 2. Court cases and federal standards resulted in better staffing. Costs increased.
- 3. In this same period, people with developmental disabilities were moving to the community. Costs continued to increase in the state hospitals because:
 - a. The fixed costs increased because of fewer residents;
 - b. Remodeling and construction occurred across the United States to meet federal ICF-MR standards;
 - c. Staffing increased or stayed level in order to reach ratios;
 - d. Unionization of public employees occurred which led to higher salaries;
 - e. Inflation had an impact;
 - f. The proportion of residents with severe/profound mental retardation in creased as less handicapped people leave; and
 - g. Indirect costs were added such as overhead and other state administrative costs in order to maximize federal financial participation.

Costs of Community Residential Facilities:

- The number of group homes in the community has increased dramatically.
- The ownership patterns can range from family, nonprofit, profit, chains, or systems.
 Family operations are the least expensive.
- Community residential facilities need a standard chart of accounts and improved cost accounting.
- Community residential facilities include capital items but not day programs or service costs.
- 5. Community residential facilities now serve all ages and all types of handicaps but the proportion who are most dependent is slightly lower than state hospitals.
- 6. Why average per diems shouldn't be compared between state hospitals and community facilities:
 - a. Costs vary by type of resident (age, level of independence, services needed, and staffing needed). Children are always more expensive than adults.
 More severely handicapped people are more costly regardless of setting.
 - b. Per diems do not contain the same items.
 - c. No standard chart of accounts exists.
 - d. No cost accounting system exists,
 - e. There are several ways of determining costs which produces different out comes in cost studies:
 - reimbursable cost reporting;
 - average per person costs;
 - fixed and variable costs;
 - unit costs; and
 - needs approach.
 - f. In Minnesota, costs vary by geographic location (urban, rural); size (6 or fewer, 17 or more); staff ratios, and special certification.

Conclusions from Past Cost Studies:

- 1. Costs don't differ if Doth types of clients are provided full array of service. (Mayeda)
- 2. Community costs are fragmented across several accounts. (O'Connor)
- 3. By adding in day programs and medical services, the difference narrows. (Mayeda)
- 4. As a treatment site, the state hospital is not as desirable as a community setting. (Jones & Jones)
- 5. Impossible to compare because no standard chart of accounts and no standard cost accounting exists. (O'Connor)
- 6. We need to add in the issue of the "family" that provides care. The family may be the most cost-beneficial approach,
- 7. Reallocation of funds must be considered if numbers of people keep moving out of state hospitals,
- 8. The Pennhurst study concluded:
 - a. State salaries and fringes are higher than community salaries and fringes.
 - b. Community staff spend more hours of direct staff time per client than Pennhurst staff.
 - c. There is a greater division of labor in state hospitals—more management, more specialists, and more medically oriented staff. Community staff do more jobs.
 - d. Savings in community are due to use of generic services.
 - e. How soon before community staff unionizes?
 - f. How long will we expect a low paid, transient work force to serve more severely handicapped people in the community?

- g. Rather than say community services are cheaper, we should say that we get more staff time for the money.
- h. Some institution programs are less expensive than community; most institutions are more expensive; average per diem reflects a wide range of people.
- 11. The gross cost of Minnesota state hospitals for FY '84 was \$159,045,479; 85.9 percent was for personnel.
- 12. Reimbursements totaled \$120,594,420 from all sources with the largest amount coming from federal Medical Assistance (\$52,656,694).
- 13. In 1980, expenditures for community services reached the same level as expenditures for institutional services for mentally retarded people. Since 1980, expenditures for community services have exceeded institutional services.

PAPER NO. 8: OPTIONS/RECOMMENDATIONS

The four options presented in this last report include:

- 1. Keep all state hospitals open but downsize.
- 2. Decentralize the state hospitals and begin state-operated, community-based services.
- 3. Increase efficiency and introduce elements Of competition in all state hospitals.
- 4. Closure of one or more state hospitals.

On page 2 of this final report, we begin with a list of all the conflicting roles. Whenever interest groups discuss what is the state's role, there is a tendency to say, "the state ought to" forgetting that we do not have a blank sheet but rather a complex set of roles including:

- provide services;
- supervise services;
- monitor and license;
- quardian;
- defendant in court;
- employer;
- negotiator;
- provider of services to employees in case of closure;

- cost containment; and
- maximize federal financial participation.

OPTION 1: Continue operation of all eight state hospitals with staff reductions or downsizing in the mental retardation units.

- The mental retardation population will continue to decline because of the Welsch Consent Decree and the waiver.
- There could be as many as 582 fewer mentally retarded people by July 1, 1987, or it could be a minimum of 300 fewer people under the Welsch Consent Decree.

Effects on Employees:

- Because all types of staff levels are stipulated in the Welsch Con sent Decree, the number of staff who could be reduced could be projected.
- The number of staff to be reduced totaled 644 positions.
- Based on historical experience, there are 1,640 separations be cause of turnover, retirements, deaths, and resignations. This number includes all employees including part time,
- It is our opinion that natural attrition can be used for down sizing as a first option compared to layoffs. Special exception is made to fill positions for health/ safety and for Welsch compliance reasons.
- The next option is to make early retirement attractive through ex tension of Rule of 85.
- The next option is to extend the Rule of 85 and to add medical insurance benefits for people until they reach age 65 years. This

option is also less expensive than layoffs.

Effects on Buildings/Energy:

- The demand for living space is going down and yet capital costs will continue for remodeling/ renovation.
- If the population can use consolidated living space, then selected buildings can be declared surplus and sold, rented, or demolished.

OPTION 2: Decentralize the state hospitals.

We looked at Rhode Island's approach in beginning state-operated, community-based services. Our state AFSCME group prepared a proposal. The Department of Human Services also created a proposal included in this report.

Effects on Residents and Employees:

- Individuals would continue to move to the community.
- Employees would be allowed to bid on positions in community settings.
- Employees would be covered under collective bargaining and pension plan.
- Retraining would be necessary.
- Space needs would be reduced.
 Property could be declared surplus,
- The state might incur new capital costs in the community or existing housing could be used.
- Economic impact would be dispersed depending on relocation of residents.

OPTION 3: Improve efficiency and effectiveness of state hospitals and introduce elements of competition.

- Management information systems would have to be in place-chart of accounts, resident tracking, etc.
- State hospitals would generate revenue as a function of services rendered.
- Each state hospital would be responsible for program mix, budgeting, marketing, and rate setting.
- No catchment areas would exist.
- Counties and case managers would be responsible for payment of service.

Effects:

- Individuals and counties would have choice of using state hospitals at a prenegotiated cost of service.
- State hospitals would still be under the same policies.
- There would be more need for flexibility than civil service currently allows. Employees would be trained and transferred based on need.
- Each state hospital would have control over buildings. There would be an incentive to conserve. (This is a real problem area be cause the state bonds and every facility is not equal in terms of buildings.)
- Proceeds of sale of property would revert to state hospitals.
- Economic impact depends on skills of state hospitals:
 - * rental value would approach fair market value;

- * laundry could be a profit center; and
- * per diems would reflect true costs.

Cautions about this approach:

- Concern about "dumping" most difficult clients or "creaming" or not providing service. The state has up to this point not rejected clients.
- True competition does not exist since the state Legislature has imposed moratoriums, sets funding levels, and has rate setting mechanisms.
- Counties have differing capacities to handle these new responsibilities.

OPTION 4: Closure of the state hospitals,

- It is extremely difficult to terminate governmental organizations.
 There is little political incentive to do so.
- Terminations are usually accompanied by a budget crisis and/or an ideological struggle.
- There is a lack of systematic evaluation studies to determine impact of closure.
- Why closure doesn't occur:
 - * guarantees instant, galvanized opposition to the idea;
 - * benefit is minimal and means "fractionally lower taxes"; and
 - * incrementalism forces most pro grams to grow rather than be terminated.

Each state hospital was hypothetically closed for purposes of this study, and the impacts were assessed.

Effects:

- -- Based on past experience, if the state does not have time and money to develop community alternatives, the residents are sent to another state hospital. Consideration must be given to:
 - * home county of each resident;
 - * where are beds available?
 - * do they match what the individual needs?
 - * if not licensed or certified, how much money is needed for bringing into compliance?
- There are several research studies of effects on residents/patients and families. Results are mixed changes in mortality, health problems, emotional changes, and adjustment issues.
- In the event of closure, we listed nine separate options for employees (pages 28-29). We also estimated the number of people who would take each option, including listing bargaining issues such as layoffs.

We summarized the research on closure and effects on employees (lowered morale, stress, physical problems, emotional problems).

We summarized the alternative uses of buildings, the cost of closure and calculated by hospital, the amount for severance, health benefits, unemployment compensation, and other costs such as heating, security, etc.

Finally, each state hospital gave their own views about closure.

SUMMARY POINTS OP TESTIMONY

BY

COLLEEN WIECK

MINNESOTA GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES

- 1. The number of people with developmental disabilities in Minnesota's state institutions has declined from 6,008 residents in 1960 to approximately 1,900 today. This trend is expected to continue,
- 2. Every state is faced with similar strategic planning questions in addressing downsizing state institutions:
 - a. what are the needs of individuals and how can services be developed to best meet needs?
 - b. How can economic impact of closure be minimized?
 - c. How can employee displacement be mitigated by natural attrition, retraining and transfer?
 - d. What are the alternative uses of buildings?
 - e. How can the public be involved in the planning process?

In 1984, the Minnesota Legislature mandated a comprehensive study be conducted by the DD Council to address these planning questions.

- 3. The most significant findings and conclusions of this nine month study include:
 - Residents: The number of individuals with developmental disabilities who live in state hospitals has declined by 68% since 1960. The individuals in state hospitals tend to be severely or profoundly mentally retarded and highly dependent in areas such as self preservation, bathing, grooming, and dressing.

Most recently, every person with developmental disabilities was assessed using a standardized scale to determine the level of assistance needed in activities of daily living. We compared the number of people who require a high level of assistance or were highly dependent. In 42 of 87 counties there were as many or more individuals with high dependence levels living in community facilities (excluding nursing homes) as compared to state hospitals. The capacity of our community programs is developing rapidly.

- Employees: As downsizing occurs, employees should be consulted on a periodic basis about their choices regarding transfers, maintaining residences, retirement, etc. Staff reductions should occur through natural attrition and early retirement options whenever possible. Voluntary transfer and retraining should be the next choice followed by layoff which is the most expensive and disruptive approach. We presented nine separate options that employees have in case of closure. We also estimated the cost of each option.
- Economic Impact: The smaller the community and less diverse its commercial or industrial base, the greater the impact of any closure or downsizing. We assessed economic impact in terms of where employees live and spend their money, state hospital employment as a percentage of total area employment, state hospital payroll as a percentage of total area income, estimates of unemployment rates if closure occurs, an estimate of indirect unemployment, impact of state hospital purchases, effect of resident spending, and effect of visitor spending. Alternative economic development strategies should be developed in cooperation with local officials to minimize the loss of public funding in case of closure or downsizing.
- Public Process: The development of a public process was a significant part of the study and included convening nine town meetings with over 5,000 people attending (362 witnesses and 80 separate organizations); over 400 letters; 202 phone calls during a "toll-free-call- in-day"; and mailing a monthly update of the study progress to over 1,500 people. As a result, the top priority expressed in the public process was concern for the residents, discussion of the quality of state hospitals and community programs, a description of unique programs, estimates of economic impact, and a discussion of the interagency relationships that exist among state hospitals and judges, sheriffs, county social services, clergy, and community providers.
- Buildings: As the population continues to decline, physical space should be consolidated. Unused buildings should be declared surplus property and sold, rented, or demolished. Alternative uses of buildings should be explored and should be compatible with the purpose of state hospitals and should not conflict with existing state policy.

- Energy Use: Energy conservation measures are important during the downsizing phase and should include execution of shared savings contracts with industries such as Honeywell, use of alternative fuels, separate metering of any leased building space, demolishing surplus buildings to eliminate heating costs, and energy improvements such as summer boilers.
- Cost: Savings accrue when individuals receive appropriate levels of service. The question of "which setting is cheaper" should be set aside given what we know about fragmented accounting procedures, differences in populations, and the lower wage levels in community settings.
- Finally, options must be presented to policymakers that thoroughly analyze the impact of the recommendation on residents, employees, local economic impact, and cost. We suggest the four options facing every state are:
 - 1. Downsizing the state hospitals
 - 2. Decentralizing the state hospitals with the state operating community services
 - 3. Introducing elements of competition in the management of state hospitals which should improve efficiency and effectiveness
 - 4. Closure of one or more of the state hospitals.

Minnesota Governor's Planning Council on Developmental Disabilities

DEVELOPMENTAL DISABILITIES PROGRAM, STATE PLANNING AGENCY 201 CAPITOL SQUARE BLDG. • 550 CEDAR STREET • ST. PAUL, MN 55101 • 612-296-4018

November 17, 1986

Colleen

TO: Ed Skarnulis, DHS Betty Hubbard, ARC Anne Henry, LADD Toni Lippert, MNASH Colleen Wilson, UCP

FROM: Colleen Wieck, Ph.D.

Executive Director

Minnesota Medicaid Reform Team REGARDING:

At this time, each of you has probably talked to your federal counterpart regarding the Medicaid Reform group meetings in Washington, DC. I have received the enclosed documents from Allan Bergman which describe the status of discussions.

There are nine states targeted by our counterparts that should meet and travel to Washington, DC, to meet with Senate Finance staff. Our team should meet with senator Durenberger's staff sometime in December 1986.

The written instructions from Washington, DC, have not been received, but I would like to propose setting up a meeting on November 25, 1986, from 1:00 p.m. to 3:30 p.m. to address our state's response to Medicaid Reform. The meeting will be held in our office conference room, Room 201, Capitol Square Building, 550 Cedar Street.

I hope as many of you can come as possible.

CW/amc

Enclosures

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ASSURING THE QUALITY OF INSTITUTIONAL AND COMMUNITY-BASED SERVICES FOR DEVELOPMENTALLY DISABLED PERSONS:

An Identification of Relevant Federal

Policy Issues

I. Background

Adherence to minimum quality standards has been a stated goal of national policy since the mid-1970's, when the federal government initially assumed a major responsibility for financing long term care services for developmentally disabled persons. But, national efforts to assure program quality generally have been pursued in a piecemeal fashion, with little, if any, attention given to the impact such actions have on shaping the overall service delivery system.

Within the past two years, however, several events have occurred which lead this observer to conclude that quality assurance is about to assume a more prominent place on the federal policymaking agenda. Among these events are:

- the widely publicized Senate hearings on resident abuse and neglect in public mental hospitals and institutions for the mentally retarded;
- * the introduction of legislation during the 99th

 Congress to revamp existing methods of surveying and

 certifying Medicaid-funded facilities and programs

 serving mentally ill and developmentally disabled

 persons:

- the initiation of an expanded series of ICF/MR "look behind" surveys, launched by the U.S. Department of Health and Human Services in late 1984 in response to Congressional pressure;
- the issuance of proposed revisions in federal ICF/MR standards, which are designed to shift the emphasis of federal-state compliance reviews from determining institutional capacity to assessing client outcomes;
- the introduction of legislation and preparation of regulations to improve the quality of care provided in Medicaid/Medicare-certified nursing homes, and more specifically, the potential side effects of these efforts for ICF/MR policy.

In addition to the above developments, there are several less dramatic but nonetheless discernible trends which suggest that quality assurance efforts will attain greater visibility and priority in the years ahead. Among these trends are:

- the growing consumer demand for high quality
 programs, as state-local service systems mature and
 provider performance expectations increase;
- the growing concern among public policymakers (at both the federal and state levels) about the rapidly escalating cost of serving developmentally disabled

- clients and the resultant demand for more sophisticated measures of performance accountability;
- the increasing pressure for a more clearly defined role for voluntary accrediting bodies in monitoring and assessing the quality of public and publiclysupported facilities/programs serving developmentally disabled persons; and
- the lack of a consistent approach to assuring quality under the ICF/MR and Section 1915(c) waiver programs, both of which authorize Medicaid payments for long term care services to developmentally disabled recipients.

The purpose of this paper is: (a) to review current developments that are likely to shape the future national policy agenda in this area; and (b) to outline some of the fundamental issues which must be resolved in order to design a more rational, holistic approach to assuring that developmentally disabled persons in need of long term care receive appropriate, high quality services. No effort will be made to recommend specific action strategies; instead, the paper attempts to describe the broad context within which future policy decisions must be made and highlight key decision points in the process. If readers gain a broader appreciation of the factors influencing national quality assurance policies/practices and are stimulated to

think further about potential solutions, the paper will have fulfilled its intended aim.

II. Factors Influencing Quality Assurance in Developmental Disabilities Programs.

While there are numerous factors influencing current quality assurance policy, it is important to recognize, at the outset, that the pressures for change do not necessarily point policymakers in the same direction. As frequently occurs in the public policy arena, countervailing forces are at work, each of which perceives the nature of the problem and potential solutions somewhat differently. In this case, all parties agree on the ultimate goal -- i.e., the establishment and maintenance of high quality services for all developmentally disabled citizens - but have unique perspectives on how this goal should be achieved .

A. Institutional Abuse and Neglect. On April 1-3, 1985, the Senate Subcommittees on the Handicapped and Labor/ HHS/Education Appropriations held joint hearings on resident abuse and neglect in state mental hospitals and institutions for the mentally retarded. Testimony by numerous witnesses at these widely publicized, emotionally-charged hearings documented widespread, often shocking deficiencies in the quality of care and treatment available to residents of public mental

institutions across the country. The subcommittees' findings led to accusations that: (a) many states were failing to meet society's legitimate obligations to some of its most vulnerable members; (b) federal enforcement of Medicaid and Medicare standards was slipshod and offered facility residents little assurance that even their most basic needs would be met; and (c) the U.S. Justice Department was not aggressively enforcing the rights of institutionalized mentally disabled persons.

During an earlier hearing, held before the same Senate subcommittees on July 31, 1984, Senator Lowell P. Weicker, Jr., Chairman of both subcommittees, criticized the Department of Health and Human Services for its failure to vigorously enforce federal ICF/MR standards, citing as evidence the findings of facilities reviewed both by his own staff and the staff of the Health Care Financing Administration. As a result, funds were added to HHS's FY 1985 budget to permit HCFA to hire 52 additional ICF/MR surveyors and the agency agreed to sharply expand the number of ICF/MR validation, or "look behind", surveys it conducted each year. HCFA's stated goal was to complete direct, federal surveys of all ICF/MR facilities with 300 or more beds, 40 percent of facilities with 16 to 299 beds and 20 percent of facilities with 15 or fewer beds.

Senator Weicker also began to castigate the Civil
Rights Division of the U.S. Department of Justice for
its lax enforcement of the Constitutional Rights of
Institutionalized Persons Act (CRIPA). Although
Justice Department officials have repeatedly denied
these allegations, the number of CRIPA investigations
launched by DOJ has increased markedly in recent years;
in addition, Department attorneys reportedly have
adopted a generally tougher stance in their negotiations with state officials.

Finally, Senator Weicker has introduced legislation aimed at clarifying the federal government's role in protecting the rights of mentally ill and developmentally disabled persons. The "Protection and Advocacy for Mentally Ill Persons Act of 1986", initially introduced by the Senator on April 23, 1985, was signed into law by President Reagan on May 23, 1986 (P.L. 99-319). A second, and potentially more far-reaching, bill was introduced by Senator Weicker on December 13, 1985. Entitled the "Quality Services for Disabled Individuals Act of 1985" (S. 1948), this measure would assign increased responsibility to the federal government for surveying and certifying Medicaid-reimbursable facilities and programs serving mentally ill and developmentally disabled persons; it also would consolidate administrative responsibility for serving DD and MI

recipients within a single HCFA bureau and authorize, as a mandatory state plan service, home and community-based services for developmentally disabled and mentally ill recipients who otherwise would require institutional care.

In summary, the general thrust of Senator Weicker's efforts over the past few years has been to expand federal oversight and enforcement activities in an attempt to eliminate substandard conditions in public institutions serving mentally disabled clients. While the Senator's interests certainly encompass the entire spectrum of service programs, there can be little question that the continued existence of inhumane conditions in some MH and MR facilities, rather than more esoteric notions of program adequacy, has been the driving force behind his initiative.

Certainly, everyone would agree that immediate steps must be taken to eradicate abusive and neglectful conditions in institutions wherever they exist. As a society that professes to care about the plight of the less fortunate and downtrodden, we simply cannot expect any citizen to live in the unspeakable squalor and degradation so graphically portrayed at the Weicker hearings. At the same time, public attention and resources can be diverted from longer range goals if we

began to focus exclusively on eradicating institutional abuse and neglect. Some would argue that one of the undesirable side effects of the Weicker initiative is that it is forcing states to spend millions of dollars to upgrade existing institutional programs, thus diverting human and fiscal resources from the more important long range objective -- i.e., expanding community-based living and programming options (see further discussion of this point under B below).

B. Program Standards. For at least a year prior to the Senate subcommittees' July 1984 hearing on HCFA's ICF/MR compliance activities, agency officials had been drafting revised federal standards governing the operation of such facilities. Without the hearings and the events which followed, however, it seems doubtful that these new standards would have been issued. The publicity garnered by the subcommittees' April 1985 hearing intensified pressure for publication of the standards; and, when they still were not released six months later, Congress included language in the 1985 reconciliation act mandating their promulgation within 60 days (Section 9514, P.L. 99-272).

As finally published in proposed form on March 4, 1986, the revised ICF/MR standards reflect a fundamental shift in the basis for determining whether a facility

is in compliance with federal requirements. Actually, the proposed standards merely codify an approach to assessing facility compliance which HCFA has been using since it launched the expanded series of ICF/MR "look behind" surveys in late 1984. Under this approach, primary emphasis is placed on determining: (a) whether the facility has an interdisciplinary process for assessing the needs of each individual client and delivering the full range of health, habilitative and supportive services he or she requires; and (b) whether individual residents are deriving anticipated benefits from such services.

For the first ten years of the ICF/MR program, federal and state surveys focused almost exclusively on compliance with environmental, physical plant, staffing and other resource-specific standards. The inherent assumption was that government's responsibility was to assure that a facility had the capability of delivering appropriate services, but was not supposed to determine whether or how effectively such services were actually provided. Therefore, the new emphasis on the provision of "active treatment" services and the assessment of client outcomes constituted a major shift in federal policy.

While most parents and professionals welcome "HCFA's new emphasis on active treatment, the secondary and tertiary ramifications of this shift in policy are just beginning to become apparent. First, the need for more and better qualified staff and improved facilities has forced some states to commit additional dollars to upgrading services in large, multi-purpose institutions in order to avoid the loss of Medicaid certification. If we were to conclude (as some have) that these facilities constitute the most appropriate living/programming environment for their current residents, it would be difficult to oppose the added outlays. But, the consensus of professional opinion suggests that many, if not all, current institutional residents could benefit from placement in smaller, community-based settings. In a fiscal environment where resources are severely constrained, a state usually diminishes its capacity to develop community-based alternatives as it increases its institutional expenditures.

Second, even if we assume that many current ICF/MR residents will continue to require 24-hour care and supervision in an "institutional" setting, an openended commitment to "active treatment" may pose significant problems. When a facility is providing its residents with little or no programming (as was found to be the case in some of the early ICF/MR "look behind" reviews), failure to comply with the "active"

treatment" mandate can be easily substantiated. However, in the absence of more objective criteria for determining acceptable threshold levels of performance, state and federal surveyors will be asked to make increasing fine-tuned distinctions between compliance and non-compliance, based entirely on their professional judgment. Under these circumstances, it seems likely that: (a) the demand for added resource commitments will continue to spiral upward, with the marginal benefits derived by residents increasingly difficult to ascertain; and (b) the gap between Medicaid and non-Medicaid funded services will widen, with federal-state resources even more heavily skewed toward the small minority of clients who reside in Title XIX-certified long term care facilities.

C. Alternative Community-Based Services. The sharp distinction between federal quality assurance policies governing ICF/MR facilities and Medicaid reimbursable home and community-based services for developmentally disabled clients has become increasingly apparent as more and more states have begun to claim Title XIX payments for the latter services. Thirty-five states presently have Section 2176 waiver programs serving a total of over 22,000 mentally retarded and other developmentally disabled persons. In addition, several states (e.g., Michigan, New York, Idaho and Ohio) bill

Medicaid for specified elements of day habilitation services under the provisions of their Title XIX state plans.

While ICF/MR facilities are required by law to comply with federal operating standards promulgated by HHS/HCFA (Section 1905(d)(l), Social Security Act), states are permitted to develop, monitor and enforce their own idiosyncratic standards applicable to Title XIX reimbursable community-based services, whether they are covered under a Section 2176 waiver or a state plan amendment.

As one of the conditions of qualifying for a Section 2175 waiver, as state must provide the Secretary of Health and Human Services with assurances that "...necessary safeguards (including adequate standards for provider participation) have been taken to protect the health and welfare of individuals...participating in waiver-financed services (Section 1915(c)(2)(A), Social Security Act). Generally, HHS/HCFA enforces this statutory provision by requiring states to restate the statutory assurances in their waiver requests and append copies of the licensing/certification standards they intend to use in the case of each category of waiver service. Generally, states are granted wide latitude in developing the types of regulatory require-

ment they feel are appropriate to the particular program/service. Most states have elected to use state licensure and certification regulations/policies applicable to existing programs and facilities as the basis for regulating waiver-financed services; modifications and additions usually are made in existing regulatory policies only when necessary to fulfill the state's Secretarial assurances.

If a state elects to cover one or more optional long term care services for developmentally disabled persons under its state Medicaid plan, federal law and regulations set forth no specific requirements governing the assurance of program quality. Again, states are free to regulate such services as they see fit.

Several recent and impending developments, however, suggest that an expanded federal role in setting standards for Medicaid-funded community programs may be on the offering. For example, early indications are that a three-year, HCFA-funded evaluation of the Medicaid home and community care waiver program will conclude that some states have done an inadequate job of monitoring services delivered under approved Section 2176 waivers. This finding could lead to pressure for uniform federal standards, especially should Congress, at some point, repeal the present waiver authority and

permit states to cover a specified range of home and community-based services under their regular Medicaid plans.

Meanwhile, under the provisions of Senator Weicker's pending Medicaid reform bill the Secretary of Health and Human Services would be directed to issue standards applicable to "...all residential facilities which furnish services under [a state's Medicaid plan]" (Section 1920(a)(l) of S. 1948), presumably including non-ICF/MR facilities that are receiving Medicaid support. intent of the bill is not entirely clear, however, since it goes on to delegate to the states responsibility for establishing necessary safeguards to protect the health and safety of clients participating in Title XL-funded home and community care services. In addition, under Section 1920(a)(3) of the bill the concept of "active treatment", as it currently applies to ICF/MR facilities, would be expanded to cover all Title XL-funded services for developmentally disabled persons.

Under the "Community and Family Living Amendments of 1985" (5. 873-Chafee; H.R. 2902-Florio), states would be allowed to establish their own program/facility standards (i.e., other than for ICF/MR-certified facilities) provided: (a) all community living facilities

and family homes were either accredited by a national accreditating body or licensed/certified by an appropriate state agency; and (b) periodic independent quality reviews were conducted of all Medicaid-funded services provided to severely disabled individuals (Section 1919(c) (1)(G) and (H), respectively). However, the Secretary also would be authorized to conduct validation reviews (Section 1919(c){2)(I)).

Should Congress decide to expand coverage of community-based MR/DD services under future Medicaid reform legislation, it seems almost certain that the tradeoffs between quality control and federal financing would be a key topic of discussion. And yet, to date, very little through has been given to the proper distribution of federal-state responsibility for setting program standards and monitoring compliance. In general, past experience suggests that federally-established standards would result in greater uniformity in the level of program quality nationwide; but the price of such uniformity would likely be higher costs, increased program rigidities and less innovation at the state and local level.

D. Accreditation. A number of state MR/DD agencies use voluntary accreditation as an integral component of their efforts to ensure the quality of institutional

and/or community-based services. In some instances accreditation is mandated under state agency regulations. For example, South Dakota, Maryland and Tennessee all require providers of community day and/or residential services to be accredited by the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (ACMRDD), as a condition of continued funding. Similarly, Arizona, Missouri, Colorado and Connecticut are among the approximately 19 states that either mandate providers of MR/DO day and/or residential programs to be accredited by the Council on the Accreditation of Rehabilitation Facilities (CARF), or recognize such accreditation as the equivalent of state certification or licensure. Finally, in fifteen states, mental retardation units on the campuses of state mental hospitals are required to be accredited by the Psychiatric Council of the Joint Commission on the Accreditation of Hospitals (JCAH); furthermore, within the past two years, JCAH has published separate standards applicable to residential facilities serving mentally retarded persons.

Besides such formal ties between accreditation and state licensing/certification/funding requirements, a number of states have used accreditation as an informal-benchmark for assessing the quality of its programs for

California and Tennessee have pursued a policy of maintaining ACMRDD accreditation at all state-operated residential facilities for the mentally retarded for a number of years.

While voluntary accreditation has achieved significant inroads at the state and local level, thus far it has no official standing under federal law or regulation. In the past, efforts have been made to formally recognize, or "deem", ACMRDD accreditation as equivalent to compliance with federal ICF/MR standards. A. regulation to accomplish this purpose was drafted within HCFA several years ago, but it was never released for public comment; since that time, interest within the agency appears to have waned -- especially since the preparation and publication of proposed revisions in HCFA's ICF/MR standards (which, ironically enough, are patterned after ACMRDD standards).

As the focus of Medicaid long term care services for MR/DO persons shifts from institutional to community-based settings, it seems reasonable to ask whether voluntary accreditation should play an official role in assuring the quality of the Medicaid-supported services delivered to developmentally disabled persons; if so, a variety of subsidiary questions must be answered, including: (a) which accreditation program(s) should be

mandated or recognized and for which specified types of programs/services; and (b) what steps, if any, should be taken to assure that voluntary accreditation programs remain accountable to publicly established policy.

E. Nursing Home Reform. In May, 1982 HCFA issued proposed regulations to modify the process of certifying nursing homes as eligible to participate in the Medicare and Medicaid programs. Included in these regulations were proposals to lengthen the recertification period of facilities with a history of past compliance and to permit the states to waive state surveys in homes (i.e., ICF and SNF facilities) accredited by the Joint Commission on the Accreditation of Hospitals.

These proposed regulations, however, drew widespread protest from consumer groups, which viewed the revisions as a step in the wrong direction — i.e., towards less stringent federal standards — and a failure to confront weaknesses in existing federal requirements.

The controversy generated by the Administration's proposal led Congress to impose a moratorium on the issuance of revised nursing home certification regulations in the fall of 1982 and, eventually, caused HCFA to contract with National Academy of Science's Institute on Medicine (IOM) for an independent study of nursing home regulations.

The findings and recommendations resulting from the IOM study were published earlier this year (Improving the Quality of Care in Nursing Homes, National Academy Press, 1986). Among the key recommendations were that: (a) the regulatory distinction between SNFs and ICFs be eliminated; (b) regulatory requirements be more resident-centered and outcome-oriented; (c) quality of life, resident rights and resident assessment be added as "conditions of participation"; (d) Medicare and Medicaid survey/certification requirements be consolidated; (e) new resident-centered survey instruments be developed; (f) positive incentives for good performance be added; (g) state survey/certification activities be 100 percent federally funded, survey qualification be strengthened and research, training and evaluation efforts be expanded; (h) federal oversight capabilities and sanctions be strengthened; (i) inspection of care be integrated into the survey process; (j) federal-state survey responsibilities be realigned, assigning states responsibility for monitoring and certifying all Medicaid/Medicare facilities (except stateoperated facilities), with the federal government responsible for overseeing state performance and monitoring/certifying all state-operated facilities and; (k) a new set of intermediate sanctions be added.

Since the release of the IOM report, HCFA has drafted new nursing home certification rules. These draft rules are now being circulated within HHS and are expected to be published for public comments either later this year or early in 1987.

Meanwhile, legislation implementing the IOM recommendations was introduced in the House of Representatives (H.R. 5450) on August 15, 1986. Hearings and committee action on this legislation is expected to occur next year. Although the outcome of these deliberations is impossible to forecast, there appears to be a growing sentiment in Congress that substantial legislative changes are essential.

While the IOM study, the related draft regulations and the pending Congressional bill all specifically exclude ICF/MR facilities from their purview, House sponsors have expressed interest in expanding the scope of their bill to encompass ICF/MR survey and certification policies when it is reintroduced next year. Given Senator Weicker's continuing interest in this area, it also is possible that there will be pressure in the Senate for similar action when nursing home reform legislation is considered .

The implications of modifying ICF/MR certification requirements within the context of general nursing home

reform legislation are unclear; however, it could make it more difficult to institute a holistic, long range strategy for improving the quality of services for all developmentally disabled Medicaid recipients, including those residing in non-ICF/MR-certified settings.

III. Key Issues to be Resolved

In order to design a more comprehensive, forward-looking quality assurance system for programs serving developmentally disabled persons, it will be necessary to answer several basic questions. Among these questions are:

1. Who should be eligible for Medicaid-reimbursable long term care services and what types of services should recipients be entitled to receive? Generally, under current law and regulations, a developmentally disabled person must meet the test of financial eligibility and need "active treatment" services provided in a Title XIX-certified long term care facility (or, in the case of waiver participants, require a similar level of care and be capable of benefiting from alternative services furnished in home or community-based settings). While, on the surface, this criteria of eligibility may appear to be rather clear-cut, in practice there are several problems associated with the present approach.

First, applicable federal law, regulations and admi-

nistrative policy place few restrictions on the types of developmentally disabled persons that can be admitted to ICF/MR facilities. Consequently, in prac-tlce the responsibility for establishing level of care criteria has been vested with each individual state. Few states, however, have tried to spell out objective criteria for differentiating between admissible and non-admissible applicants (other than in the most general terms) and, as a result, the composition of the current ICF/MR population varies considerably from state to state.

Rumors indicate that HCFA officials are planning to terminate the provider agreement of at least one small ICF/MR-certified facility on the grounds that its residents do not require active treatment services. This move is intended to signal the states that HCFA will no longer tolerate the certification of ICF/MR facilities housing mildly handicapped individuals who require few, if any, training and habilitation services. While such action may have an impact on certification practices in some states, it will not resolve the broader question of how eligibility parameters are established.

Second, because the underlying purpose of Medicaidreimbursable long term care services is the provision of medical and remedial care, it has always been dif-

ficult to maintain the integrity of the "active treatment" concept within the context of the overall Title XIX program. One manifestation of this problem is HCFA's long-standing prohibition against Medicaid payments for educational and vocational training services. Despite the issuance of HCFA guidelines to clarify the difference between reimbursable habilitation services on the one hand and non-reimbursable educational and vocational training activities on the other (State Medicaid Manual Transmittal No. 21, dated September, 1986), the basic issue remains unresolved. Simply put, provider agencies face enormous fiscal disincentives to training severely handicapped clients for integrated employment when, as a consequence, they are likely to lose their Medicaid eliqibility. If most existing ICF/MR residents and MR/DD waiver recipients were capable of achieving true economic and social selfsufficiency, few, if any, barriers would exist; but, the fact is that most current ICF/MR and waiver recipients would be unable to retain employment and live in the community without ongoing support and assistance from the state-local MR/DD service system.

Congress recently took an initial step toward addressing this problem by adding a new definition of "habilitati on services" to the 1985 reconciliation act. This definition allows the states to claim Medicaid

reimbursement for educational, prevocational and supported employment services on behalf of certain HCB waiver recipients, when such services are not available through state-local education or vocational rehabilitation agencies. Only waiver recipients who were previously institutionalized, however, are eligible to be covered by this new definition. In other words, the new definition does not apply to ICF/MR residents and a majority of DD waiver recipients.

Third, the existing assumption that eligibility can be defined in terms of the intensity of a client's service need also is being challenged. It is not simply a question of the appropriateness of the service provided (i.e., outcome-oriented vs. care-oriented), but whether a client must receive a specified threshold level of services in order to qualify for Medicaid reimbursement. In this respect, HCFA's proposed ICF/MR regulations, with their emphasis on the provision of a "continuous" program of active treatment services throughout the client's day, could serve as a disincentive to moving clients toward reduced dependency on the service system. If the "reward" for less dependency is loss of Medicaid eligibility, the provider will have a powerful, built-in inducement for keeping the client fully programmed and dependent.

In summary, it will not be possible to design an effective quality assurance system until a national consensus is reached on: (a) the composition of the target population for such services; (b) the types and intensities of services that qualify for Medicaid reimbursement; and (c) the acceptable programmatic goals for MR/DD clients participating in Medicaid-financed long term care services.

2. How should the appropriateness and quality of services be assessed? As pointed out earlier, HCFA has strongly emphasized, both through its look behind initiative and in its proposed rewrite of federal ICF/MR standards, the importance of assessing client outcomes, rather than judging a facility's compliance simply in terms of input and process measures. While conceptually this approach has considerable appeal, since it focuses attention on the end product of facility services, objective measures of client attainment or progress have yet to be developed and standardized. Thus, the results of federal look behind surveys are based almost entirely on the professional judgment of survey team members, which are subjective in nature and, therefore, susceptible to variability.

As long as the primary purpose of the survey is to "weed out" facilities which are substantially out of compliance with applicable standards, this approach may work reasonably well. Clearly, it is superior to the old method of basing certification (and recertification) decisions on such pseudo-measures of quality as physical plant specifications and record-keeping requirements.

When compliance expectations are not stated in clear, objective terms, however, they can easily become "moving targets", changing according to the predilections of the particular survey team or the fads of the moment. Ever if it were possible to limit the purpose of certification reviews, the question remains: should the quality of a facility's program be judged solely on its capacity to comply with minimum standards or are there other dimensions of quality that need to be assessed?

Earlier this year, HCFA announced that it was instituting a new outcome-oriented survey process for Medicare and Medicaid-certified skilled nursing and intermediate care facilities. This new process, commonly referred to as the Patient Care and Services (PaCS) survey, is based on a series of federally-supported research and demonstration projects dating back to 1982. It is important to note that a program to develop and field test similar instruments for sur-

veying ICF/MR facilities was considered by HCFA about four years ago; ultimately, however, this proposal was rejected due to a sharp reduction in the agency's research and demonstration budget.

3. Should voluntary accreditation play a more formal role in assuring the quality of Medicaid-supported facilities/programs. Currently, some institutional and community facilities supplement the findings of mandatory licensing or certification reviews with accreditation surveys. The only problem is that there are few incentives for a facility to seek accreditation, other than the psychic rewards of peer recognition.

One frequently heard (and widely supported) proposal is to officially recognize accreditation as the equivalent of meeting Medicaid certification standards. The notion of "deeming" accreditation has a certain inherent appeal, since it would ensure that reviews are conducted by unbiased, skilled third party surveyors and avoid the need for duplicative surveys. But, there are both technical and policy barriers to deeming the results of accreditation surveys. First, Congress would have to decide which accreditation programs to recognize, or delegate decision making authority to the Secretary. As noted earlier, three national accrediting bodies currently review MR/DD facilities and

programs. Not only are there significant overlaps between the types of facilities/programs reviewed, but each of these accrediting bodies used quite different standards and methods of assessing compliance.

Second, assuming that the above issue could be resolved, HHS/HCFA officials presumably would have to review each applicable set of accreditation standards and establish levels of equivalency, in order to ensure that all of the requirements of federal ICF/MR standards are covered. Otherwise, the Secretary could be accused of reneging on his standard setting responsibilities under Section 1905(d)(l) of the Act.

Finally, Congress and/or HHS/HCFA officials would rave to weigh the need for specific policies to assure that voluntary accrediting bodies are held accountable to federal law and regulations in carrying out their quasi-public responsibilities. HCFA's experiences in deeming JCAH accreditation of acute care hospitals and psychiatric facilities highlights the potential pitfalls of over-reliance on voluntary accrediting bodies that are controlled by "the industry".

4. How should responsibility for quality assurance functions be distributed among federal and state governments? As pointed out earlier in this paper, there is a sharp distinction between the federal government's

role in assuring quality in ICF/MR-certified facilities as opposed to in alternative, community-based services financed with Medicaid dollars. Any attempt to restructure existing federal quality assurance requirements must address the central question of which level of government will be responsible for carrying out specified standard setting, monitoring and enforcement functions.

As the federal government's role in financing home and community care services grows more and more prominent, it seems inevitable that pressure for additional federal accountability measures also will increase. The key question is: what role should the federal government play in the process. Some, no doubt, will argue that HCFA cannot regulate the quality of Medicaid-funded services (whether institutionally or community-based) without establishing national standards against which compliance can be measured. However, uniform national standards could have some distinctly undesirable side effects. National community service standards could undermine the flexibility and responsiveness of existing state service systems, by forcing them into a narrowly defined, typological straight jacket; it also could result in higher program costs without comparable improvements in services to eligible clients.

But, is it possible to exercise federal oversight effectively without national standards? One alternative might be to spell out in federal law certain basic requirements that must be covered in program standards (as proposed in Senator Weicker's pending bill; S. 1948), while leaving the actual development and promulgation of regulatory standards to the responsible state agency -- perhaps subject to review and approval by the Secretary. Another approach would be to authorize the Secretary to conduct validation reviews of state standard-setting and enforcement activities (as proposed in the "Community and Family Living Amendments"). A possible variation on the latter theme would be to authorize the Secretary to contract with a national accrediting body or another qualified organization to complete validation reviews for the Department.

Regardless of the approach used, the general goal should be to strike a proper balance between the flexibility necessary to successfully operate community programs in 51 diverse jurisdictions and the federal government's need to maintain accountability for Medicaid expenditures.

5. How can standards be maintained in large institutions which are scheduled to be downsized without jeopar-

dizing a state's capability of carrying out such deinstitutionalization plans? The increased scrutiny directed at large ICF/MRs over the past two years, no doubt has led to improvements in the availability and quality of services provided to facility residents. But, as noted earlier, some would argue that the cost of these improvements is undermining the states' ability to develop the community-based alternatives necessary to meet their deinstitutionalization goals.

The inherent trade-offs will not be resolved easily. On the one hand, it would be irresponsible to argue that present institutional resident;, many of whom have live in an institution for most of their lives, deserve less than a fully compliant living and programming environment. Yet, for institutional residents who could benefit from placement in community-based programs, it seems shortsighted and wasteful to commit additional federal and state dollars to facilities or units of facilities that could be closed within the foreseeable future (e.g., 2 to 3 years) if the state were permitted to fulfill its own community placement goals.

Legislation to allow states the choice of downsizing a non-compliant ICF/MR facility was approved by the Senate Finance Committee in September, 1985, as a rider

to a reconciliation bill. But, by the time this provision [Section 9516 of COBRA) was enacted into law, so many qualifiers had been added that a state would be forced, in effect, to both upgrade institutional services and phased down its population. Unless a way is found to circumvent this problem, in some states the development of community services will be slower and total federal-state Medicaid costs higher than otherwise would be the case.

V. Conclusion

The purpose of this paper has been to outline current and forthcoming issues that are likely to influence the composition of future federal quality assurance policies with respect to Medicaid-financed services for developmentally disabled recipients. Whether the reader agrees or disagrees with the "diagnosis" offered here, hopefully the paper will help to stimulate further discussion concerning critical issues presently facing federal and state policymakers.

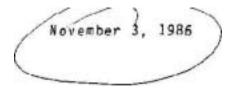
Robert M. Gettings

October 8, 1985 Revised, October 31, 1986

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Minutes

Ad Hoc Discussion Group on Medicaid Legislation



Participants

Susan Ames-Zierman, National Association of Developmental Disabilities Councils

Allan Bergman, United Cerebral Palsy Associations Marty Ford, Association for Retarded Citizens, U.S. Sob Settings, National Association of State Mental Retardation

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The second meeting of the Ad Hoc Discussion Group on Medicaid Legislation came to order at 1:10 p.m. on November 3, 1986.

Review of the Minutes

Participants were asked to review the minutes of the October 29 meeting and provide feedback. In general, everyone agreed that the minutes accurately summarized the group's discussion. One minor change was made in the second sentence of paragraph two on page four of the minutes. The revised sentence should read "...Those in favor of mandatory case management services expressed the belief that a statutory mandate is a necessary pre-condition to assuring the provision of quality services" (change under lined).

Regarding the involvement of other groups in the activities at the Ad Hoc Group, it was decided to discuss this issue at a future meeting. Two alternatives were suggested: (a) brief interest groups on the status of the Ad Hoc Group's deliberations at an open meeting of the CC DO Task Force on Medicaid; and/or (b) share copies of the meeting minutes with other interested groups.

Political Strategies

Next, participants turned their attention to possible political strategies for seeking strong bipartisan support for any reform proposal emerging from the group's discussions. ARC/US representatives told the group that, based on instructions from its Governmental Affairs Committee, they would be meeting with

Christy Ferguson on Tuesday, November 4 to discuss Senator Chafee's plans for introducing a revised Medicaid reform bill next year. They also hoped to determine if Senator Chafee planned to work with Senator Weicker in drafting a compromise bill that might incorporate features of both the "Community and Family Living Amendments" (S. 873) and the "Quality Services for Disabled Individuals Act" (S. 1948).

Since Senator Chafee's staff reportedly is in the process of drafting a revised version of CFLA for introduction next year, several participants noted the urgency of completing a set of specifications for reform legislation just as soon as possible, in order to: (a) impact on the Chafee drafting process; and (b) involve other Finance Committee members in the process, so the eventual bill will not be perceived to be exclusively a "Chafee initiative".

The group also decided to await the outcome of Tuesday's election before finalizing the list of senators who should be the target of an inter-organizational lobbying initiative, aimed at enacting long term care reform legislation. Depending on whether the Democrats or the Republicans control the Senate, it was noted, the list of "target" senators might change.

The group then turned its attention to a discussion of "state infrastructure" and related state plan requirements within a piece of Medicaid reform legislation. The discussion generally followed Allan Bergman's outline, entitled "Proposed Items for 'Infrastructure' and 'Capacity Building' in State Plan Development" (Attachment A). The points that were discussed are summarized below.

I. Client Coordination

Everyone concurred that it would be necessary to define "case management" before the concept could be operationalized in federal law. Furthermore, it was agreed that two distinct but interrelated types of case management, or client coordination, are essential: (a) individual case coordination; and (b) systems level coordination. The former type of coordination is necessary within each major service program or facility; it involves the day-to-day tracking of the delivery of services to the client in accordance with his or her IHP, as well as making necessary adjustments in the client's service plan to accommodate any changes in his/her needs over time. contrast, systems level coordination is essential to assure that: (a) the client receives all of the appropriate services he or she needs, delivered in the proper sequence, intensities and quality; and (b) the activities of two or more agencies serving the same client are properly dovetailed.

Participants agreed that ACMRDD accreditation standards should be examined in an effort to distinguish between these two types of client coordination, both in terms of nomenclature and differential functional responsibilities. [N.B., ACMRDD standards define only one level of case management -- individual program coordination -- and specify that each service agency must designate a staff member responsible for carrying out this function on behalf of each of its clients (see Attachment B).]

Everyone present agreed that an employee of an agency responsible for the direct provision of. day and residential services to the subject client cannot effectively act as a systems level coordinator, due to the potential for conflict of interest. Because of the vast differences in state service systems and the lack of objective comparisons between different administrative models, most of the participants agreed that it would be impractical to mandate, 1n federal law, the adoption of a specific type of client coordination system. Instead, it was agreed that the statute should spell out (under the state plan requirements) certain basic principles that a state must follow in designing a case management system, while allowing each participating state to determine the best way of organizing a system that adheres to such statutory principles. group also agreed to use the term "client service coordination", rather than "case management", due to the negative connotations of the latter term.

II. Staff Training and Development

Everyone agreed that a state should be required to describe in its state plan the policies and procedures it will adopt to assure that:

- all personnel delivering services supported in whole or in part with funds appropriated under this legislation have received pre-service education and/or training appropriate to the nature of their duties;
- Every agency providing Medicaid reimbursable ser vices under this legislation will maintain written personnel policies that comply with the provisions of relevant state laws and regulations;
- in-service training and continuing education ser vices are furnished to the staff of agencies pro viding Medicaid-reimbursable services to developmentally disabled persons.

The group also agreed that the Secretary should be responsible for developing and field testing competency-based

standards for use in hiring service agency staff and assessing staff performance. Given the present state-of-the-art in this area, however, a majority of those present were reluctant to mandate, in federal law, that states adopt and utilize such competency-based standards. It was also agreed that the cost of pre-service orientation, inservice training and continuing education should be considered reimbursable administrative costs under a state Medical Assistance plan.

III. Statewide Capacity Building

There was a consensus among the participants that the states should be required to spell out in their state plans the steps that will be taken to assure that providers (and potential providers) have access to needed technical assistance and expertise in designing and implementing new and expanded community-based programs. In this regard, states would be expected to specify the methods and procedures that will be used to make such capacity building resources available.

IV. Statewide Crisis Intervention and Individualized Support Services

All participants agreed that states should be required to spell out, in their state plans, the methods that will be used to assure that crisis intervention services are available, in order to prevent the need to relocate clients with special behavioral, sensory, physical or medical problems to more restrictive living environments. The expectation is that such services normally would be provided at the client's regular place of residence or program site, not in isolated or segregated settings; furthermore, the aim of such services would be to help the family, surrogate family or the local provider agency acquire the skills necessary to successfully serve the particular client, rather than separating him/her from an environment where he/she otherwise would enjoy greater opportunities for independence and/or community integration.

Using the example of clients with severe behavior problems, one group member noted that several states have set up or are establishing segregated programs to remove such clients from their regular program or living environment. After they have been removed and, ostensibly, retrained, staff in the regular program don't want them back. It was noted that this problem also applies to other low incidence problems (e.g., serving deaf-blind-retarded individuals).

V. Quality Assurance

Everyone concurred that quality assurance is a major topic that will have to be discussed separately at a future meeting.

VI. Protective Services

All participants agreed that states should be required to specify in their state plans the methods and procedures to be used in assuring that all children and adults have access to protective services. The agency or agencies providing protective services should meet the following minimum criteria:

- it should have access to any service program or facility, as well as all relevant records on a client, 24 hours a day;
- it should have standing in court to take legal action against a facility or program;
- it should be independent of any agency responsible for delivering or overseeing the delivery of direct services to such clients; and
- it should have the legal capacity to intervene on behalf of both disabled children and adults.

A state may elect to have an existing agency carry out protective service functions (e.g., a P & A agency or a child welfare agency). But, if it does so, it must assure that the agency fully meets the above criteria.

VII. Institutional Depopulation and the Development of Community Alternatives

After considerable discussion, the group agreed that a state should be obligated to include in its state plan a detailed multi-year strategy for developing community-based services (including a full array of day, residential and support services). This key aspect of the state plan should contain, at a minimum:

- a selection policy and criteria that assures all eligible or potentially eligible DD individuals equal access to community-based services, regardless of their current place of residence or the nature/severity of their handicapping con ditions;
- a specific component that spells out the steps the state will take to assure that the current aggregate population of larger Medicaid-certified resi-

dential facilities (i.e., with 16 beds or more) will-be reduced by no less than 50 percent within a period not to exceed ten (10) years from the date of approval of the state plan. [N.B., The assumption of the group was that ten years would be an outside limit, but many states would elect to move more rapidly in order to free up additional resources for community-based services.]

- a specific component that outlines the steps the state will take, over the ten-year period, to assure the expanded availability of services to qualified recipients who are living with their natural or adoptive families or in other non-Medicaid-certified facilities;
- a multi-year plan for systematically increasing the proportion of total federal, state and local dollars obligated for community-based vs. institutional services, as the state implements the deinstitutionalization and community expansion components of its plan [N.B., Under the proposed arrangement each state, over the ten-year period, would act as its own "control group"; thus a state with a 70:30 institutional-to-community expenditure ratio would not be obligated to achieve the same ratio, at the end of the ten-year period, as a state which started with a 30:70 ratio.]

The participants also agreed that states would be obligated to sat new deinstitutionalization goals after the original ten-year period ended. However, rather than attempting to specify those goals in the legislation, the Secretary of Health and Human Services would be required to study the impact of serving developmentally disabled persons in alternative residential and day program settings and report his findings to Congress. It is anticipated that this report, which would be due, in final form, eight years after the enactment of the original legislation, would form the basis for setting new "communitization" goals in subsequent amendments to the statute.

Some of the participants felt that statutory treatment of deinstitutionalization after the first ten years deserves further discussion. Therefore, it was agreed that the group would return to this topic at a future meeting.

VIII. Incentives and Fiscal Impact

The group agreed that it would be desirable to give states incentives to develop certain types of community-based services, especially in-home support and training services for

families caring for severely disabled persons at home and non-facility-based residential services. However, no generally acceptable suggestions for accomplishing this end were offered. The idea of a higher, differential matching ratio was mentioned again, but it was pointed out that: (a) if states were permitted to claim reimbursement for services not previously eligible for Medicaid cost sharing, the increased cost of the program to the federal government would be prohibitive (probably killing chances for enactment of the legislation); (b) but, if states were only allowed to claim reimbursement for services initiated after the enactment date of the legislation, those jurisdictions with a substantial investment of state general revenue dollars in such programs would be treated unfairly.

One member of the group pointed out that this dilemma, not only applied to the use of differential matching ratios, but strikes at the very core of the problem of designing basic reform legislation. As long as benefits remain an openended entitlement (a basic assumption accepted at the group's initial meeting), when service eligibility and coverage are expanded (as also agreed to at the first meeting) you face a choice between a rapid escalation in the federal cost of the program or locking in the interstate inequities associated with the existing mal-distribution of federal Medicaid receipts.

The group agreed that this issue requires further discussion and would be raised again at a future meeting.

There was a consensus that the agenda for the next meeting would proceed as follows:

- quality assurance [(N.B., Bob Gettings distributed copies of a paper on this subject he had prepared for discussions with Representative Waxman's staff on nursing home reform legislation; Allan Bergman indicated that he had sent copies of two relevant papers to all members of the group , by mail.]
- state and federal administration
- living arrangements
- other planning considerations
- interstate equity
- employee protection

Page 8

The next meeting is scheduled for Monday, November 10 at 1:00 p.m. in the ARC/US's conference room.

Proposed Items for "Infrastructure" and "Capacity Building" in State

Plan Development

PROPOSED ITEMS FOR "INFRASTRUCTURE" AND "CAPACITY BUILDING" IN STATE PLAN DEVELOPMENT

- Statewide Independent Service Coordination (case management)
- 2. Statewide Staff Training and Development
 - A. Competency Eased Staff Certification
 - B. Minimal Requirements for Employment
- 3. Statewide Technical Assistance
 - A. For New Service Development
 - B. For Program Conversion
- 4. Statewide Crisis Intervention Team(s):

To be Deployed to Place Where Inappropriate Behavior Exhibited

- 5. Quality Control Mechanisms:
 - A. Independent
 - B. Accessible by Public
- 6. Statewide Adult Protective Services
- 7. An Institutional Depopulation Plan Which Emphasizes Individuals with the Most Complex Needs Relocating to Community Services First.
- 8. IHP/IPP
 - A. To Focus on Practical Life Skills to Reduce Dependency on Paid Staff
 - B. Dollars Follow Person Based on Need
- 9. Due Process/Procedural Safeguards

ACMRDD Standards

Section 1.5, Individual Program Coordination

36 ac mrdd standards ATTACHMENT B

1.5 Individual Program Coordination

Definition

Individual program coordination is the process by which responsibility for implementation of the individual's program plan is established. The process includes providing support, obtaining direct services, coordinating services, collecting and disseminating data and information, and monitoring the progress of the individual.

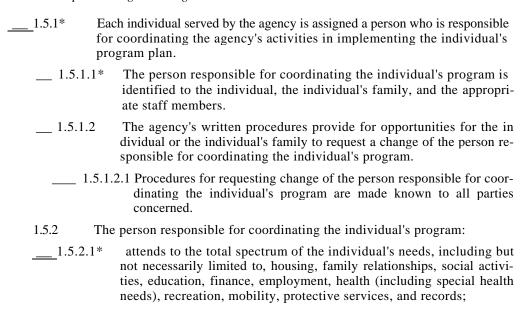
Principles

Each agency providing services to an individual should assign a person to coordinate the agency's activities in implementing the individual's program plan. This person should be responsible for implementing the agency's role in the individual program plan and for assuring that all relevant staff, as well as the individual and, when appropriate, the individual's family, focus their efforts on attaining the objectives specified in the plan. The individual program coordination process should be terminated only when services to *the* individual have been terminated.

When two or more agencies provide services to an individual, an agency should be designated to be responsible for coordinating the individual's overall program plan.

Standards pertaining to all agencies

1.5.2.2*



as needed by the individual;

locates, obtains, and coordinates services outside and inside the agency,

1.5.2.3	secures relevant data from other agencies providing 3ervice, to keep :he individual program plan up to date;
1.5.2.4	provides documentation concerning coordination of the individual program plan;
1.5.2.5*	monitors the operation of the services that are provided the individual
	in accordance with the individual program plan;
1.5.2.6*	intervenes when necessary to assure implementation of the plan;
1.5.2.7	requests, when necessary, review of the individual program plan by
	the individual's interdisciplinary team; and
1.5.2.8*	facilitates the transfer of the individual to another service or agency, when such transfer is appropriate to meet the individual's needs.
de	nen two or more agencies provide services to an individual, an agency is signated to be responsible for coordinating the individual's overall invidual program plan.

Minutes



Ad Hoc Discussion Group on Medicaid Legislation

October 29, 1986

Participants

Susan Ames-Zierman, National Association of Developmental Disabilities Councils

Allan Bergman, United Cerebral Palsy Associations Elizabeth Boggs, Association for Retarded Citizens/U.S. Marty Ford, Association for Retarded Citizens/U.S. Bob Gettings, National Association of State Mental Retardation

Program Directors Patty Green Roth, National Association of Protection and

Advocacy Systems Ruth Katz, National Association of State Mental Retardation

Program Directors

Paul Marchand, Association for Retarded Citizens/U.S. Tom Nerney, The Association for Children and Adults with Severe

Handicaps

Procedural Agreements

The group concurred that its basic goals would be:

- to reach agreement on shared values and structural features that should be reflected in any future Medicaid reform bill(s);
- to identify and resolve problem areas that fray prevent or impede the enactment of such legislation; and, assuming the first two goals are achieved,
- to develop strategies for the introduction and eventual enactment of the legislation.

The ultimate product of the group's deliberations, hopefully, will be a set of specifications for Medicaid long term care reform legislation, rather than a draft bill. It was pointed out that if and when the group reached the point where all parties were satisfied with the broad outlines of a legislative approach, it would be important to engage key Congressional staff in the actual process of drafting the bill, so they had a "buy in".

Participants also agreed that, once a strategy is developed, it would be important to identify how it should be presented to other interested organizations as well as members of Congress and their staff. While the group took cognizance of the potential risks involved in excluding any interested parties from the discussion, it was agreed that the group should remain small at least until the major framework of the proposal was hammered out. However, it was also agreed that a procedure should be worked out

to keep other interested organizations (i.e., other members of the CCDD Task Force on Medicaid) informed of the group's progress.

It was decided that Bob Settings would act as a facilitator to keep the discussion on track and Ruth Katz would take notes. Using Allan Bergman's initial outline of Issues/Principles regarding Medicaid Long Term Care Reform (attached), the group began considering substantive topics at approximately 1:30 p.m. The major issues addressed are summarized below.

I. Declaration/Intent/Purpose

There was a consensus that it would facilitate the discussion if this topic were postponed until the end of the process. At that time, it should be easier to draft a meaningful declaration of purpose.

II. Eligibility

All the participants agreed that eligibility for Medicaid long term care services should not be artificially constrained by the locus in which services are provided (i.e., a certified LTC facility) or the recipient's hypothetical level of care need (i.e., requiring an "institutional" range of services). Vet, at the same time, eligibility would have to be constrained to make any reform package saleable. There was a consensus in the group concerning the following points:

- eligibility should be delineated in a manner that is conceptually understandable;
- the definition should he tied to available data sources, in order to promote inter-program linkages and clear cut eligibility determinations;
- the eligible population should be restricted to individuals who meet the SSI disability criteria, became disabled prior to age 22, and meet the economic needs test for Medicaid benefits.

Furthermore, the group agreed that three additional issues should be dealt with in delineating the criteria of eligibility for Medicaid reimbursable LTC services: (a) selective exclusions to the deeming of parental income or some type of sliding scale system of co-payments should be instituted so that severely disabled children living in a middle income family that does not otherwise meet the economic means test may receive Medicaid reimbursable LTC services; (b) the legislation should include language to avoid disenfranchising otherwise eligible recipients in states

that use a stricter criteria of disability than the SSI test (i.e., the so-called 209(b) states); and (c) income disregards for recipients with earnings should be authorized to assure that they retain a reasonable portion of their wages as well as an incentive to increase earnings over time. Since we will need to answer assertions that Medicaid is, after all, a program intended to be limited to low income individuals and families, it will be important to gradually increase the individual's or family's financial liability for services as earnings or (in the case of families) income/resource levels rise.

To resolve issue(b) above, it was determined that there should be a national income eligibility standard or some other means of circumventing the problem posed by Section 209(b) states -- perhaps something akin to language in the 1986 reconciliation bill (Section 9404, H.R., 5300] which establishes a new mandatory Medicaid coverage category for severely handicapped persons receiving Section 1619(b) benefits (including those in Section 209(b) states).

There was some discussion of the merits of proposing an age of onset later than 22 years; but, it was decided that if advocates for severely handicapped, non-developmentally disabled persons wish to lobby for a higher cutoff age, they could do so.

III. Services

All persons present agreed that room and board should not be considered a reimbursable service under long terra care reform legislation. In addition, there was general agreement that services should be "debundled" (i.e., a client should be eligible to receive an individually tailored service package without having to demonstrate a need for a comprehensive array of services (as is currently the case under Medicaid's LTC policy).

The group decided to add two additional subtopics under the "services" heading: (a) the inclusion of language requiring the development of individualized habilitation plans through an interdisciplinary team process; and (b) mandatory versus optional services. Most participants appeared to favor an extensive statutory list of optional services from which a state could choose, in order to account for the differing service needs of individuals included in the target population. By implication, the group appeared to be saying that the services listed in Section 1919(a)(2) of the Community and Family Living Amendments might be a useful starting point for discussion.

However, no final decisions were reached on particular services that should be included or excluded.

There was a discussion about whether case management and protective services should be mandated services. Those in favor of mandatory case management services expressed the belief that a statutory mandate is a preconviction to assure the provision of quality services. Others felt that it would be more important to mandate service delivery capabilities (including a case management system) than to require that case management be offered as a mandated service. Still, others said mandatory intake services might be a better idea, since it would be counterproductive to require the development of full service plans for clients, if, in fact, "hard" services would not he available to them in the foreseeable future. On the other hand, no one appeared to disagree that all recipients of Medicaid reimbursable LTC services should receive case management services. The group agreed to come back to this issue at a subsequent meeting .

The consensus appeared to be that protective services should be mandated in any reform legislation, but no final conclusion was reached on this point.

There was general agreement that DD recipients of Medicaid reimbursable LTC services should retain their eligibility for "generic" Title XIX benefits. In addition, the group discussed whether it would be sensible to make a clean break between acute Medicaid services (* or which eligible DD recipients would remain eligible) and long term care services (which would be furnished to DO recipients exclusively through the new statutory authority.) Those in favor of a clear distinction argued that retention of some LTC eligibility would be difficult to defend and administer. The counter argument was that states should be given the choice of either covering a service (e.g., home health care) under its general program or under the specific provisions related to LTC for DD recipients.

IV. Fiscal Issues

Everyone present agreed that fiscal considerations would probably be the most difficult to tackle; "the basic question", one participant said, "is how to create a package that broadens both the array of reimbursable services and the eligibility base, and still have a politically saleable product". Everyone agreed that in many large states, with high Medicaid usage, a major selling point of any reform strategy would be its cost effectiveness. The dilemma is that the reform must encompass a better* set of options for the future of the service system,

but, at the same time, future costs must be kept within reasonable bounds if such reform legislation is to be enacted. There appeared to be a consensus that no one wished to propose legislation that would involve a federal expenditure cap; and, yet, it wasn't clear that a convincing fiscal impact analysis could be developed in the absence of some type of expenditure limit. It was agreed that the issue of fiscal impact would require further in-depth discussions.

The issues of "interstate equity" and "state flexibility" were added as discussion topics under the "fiscal issues" heading.

There was some discussion regarding the use of higher matching ratios to reward states/providers that developed non-facility-based residential programs. A majority of those present seemed to feel that differential matching would not be an effective strategy. Non-facility-based care is certainly a desirable alternative to congregate care for many recipients, one participant pointed out, but avoiding out-of-home care in the first instance also is an important program goal.

The group decided to reconvene on Monday, November 3, 1986 in the ARC conference room. The discussion will proceed in the following order:

- state/local infrastructure
- other administrative topics
- quality assurance
- systemic planning

Everyone agreed to reserve November 10 for another meeting, and, if necessary, all day an November 19. Hopefully, by the latter date the group will have reached consensus on the broad outlines of legislative specifications.

MEDICAID LONG-TERM-CARE REFORM

ISSUES/PRINCIPLES (a beginning list)

I. Declaration/Intent/Purpose

- A. Families
- B. Home/Community
- C. Independence, Productivity, Integration
- D. Other

II. Eligibility

- A. SSI
- B. Federal Definition of Developmental Disabilities
- C. Age of Onset: 22, 35, other
- D. Other

III. Services

- A. Individualization -- Creative Supports
- B. Non-Facility Based/No "Institutional Bias11
- C. Families/Home
- D. Mandated List for States
- E. Optional List for States
- F. Waiver of Statewideness
- G. IHP/Interdiscipiinary Process
- H. Mandatory vs. Optional Services
- I. Other

IV. Fiscal Issues

- A. Incentives
- B. Disincentives
- C. Reimbursement Methodology
- D. Caps
- E. Interstate Equity
- F. State Flexibility
- G. Other

V. Quality Assurance

- A. Standards -- Facility/Program/Staff
- B. Monitoring -- By Whom
- C. Outcomes
- D. Appeals/Grievance/Due Process Mechanisms
- E. Other

VI . Administration

Page 7

- A. HCFA Structure
- B. State Structure
- C. Minimum State "Infrastructure" for Capacity Building
- D. Other

VII . Living Arrangements

- A. Size
- B. Distance
- C. Clusters
 D. Grandfathering
- E. Other

VIII. "Institutional" Phase Down

- A. Time
- B. Cap
- C. FFP Role D. Other

IX. Planning

- Time
- B. Public Participation
- C. Assurances
- D. Other
- Employee Protections Х.

TO: Betty Hubbard
Anne Henry
Toni Lippert
Ed Skarnulls
colleen Wilson

FROM: Colleen Wieck, Ph.D. Executive Director

REGARDING: Medicaid Reform Follow-Up

In follow-up to our meeting on November , 1986, I have prepared in outline form a set of questions and answers that can be used in any meetings with Senator Durenberger, his staff, or the Senate Finance staff.

Please give me some of your ideas and return these sheets to me within 10 days. Any notes will be of assistance. You do not have to prepare final copy.

Thank you for your attention.

CW/amc

Enclosure

ESSENTIAL COMPONENTS OF MEDICAID REFORM

- Remove the institutional bias of Medicaid.
- Support the family; Do not provide incentives for out-of-home placement.
- Provide an array of services using existing housing and space.
- Supported Employment is preferred over day programs that foster activities.
- Technology can allow environments to be adapted.
- Face the tough issues: Staff dislocation (employee issues), economic impact of local communities, and vacant buildings.
- Each state must be encouraged to develop best practices.

1. Why is Medicaid Reform necessary?

- a. Medicaid expenditures have risen at a rapid rate and is currently the equivalent of the fourth largest U.S. corporation. Mobil Oil is third largest, and Ford Motor Company is fifth largest. Dramatic growth has occurred because of utilization, additional eligible population groups, and inflation.
- b. Federal policy has emphasized community programs since President Kennedy's proclamation in 1963. Yet federal funding has continued to be biased toward institutions. Even as the population of state institutions has declined from 195,000 in 1967 to less than 100,000 today, federal funds has increased from \$70.0 million in 1972 to \$5.2 billion today.
- c. The fundamental problems of institutions are the depersonalization, lack of respect, and dignity. increasing expenditures can never address these problems.
- d. Waiting lists.

- What should the service system look like if Medicaid Re form occurs?
 - a. State institutions would be phased out. Minnesota has 1,700 people today in seven regional centers. If the rate of population at 200 per year continues, there would be no one living in regional centers in ten years.
 - b. Community ICF-MR facilities.
 - c. Alternatives such as SILs, Family Subsidy, SLAs, etc.
- 3. What is the financial impact of phasing out institutional care and development of community and individual alternatives?
 - a. The trends in expenditures are presented in graph form. By not phasing out institutional care, the per diems of regional centers will double from \$159 per day to \$ __ per day in the next _ years.
 - b. Several community ICF-MR providers have already or are planning to decertify beds in their facilities. The changeover to waiver funding has eased the transition.
 - c. Medicaid is not an efficient program because individuals receive too much service or too little service. The options are limited to ICF-MR facilities (24 hours of care) or waiver options.
- 4. How will quality be monitored?
- 5. Will group homes have to be built for everyone who leaves an institution?
 - No. Existing housing, including apartments, may be purchased or rented. (Links, January 1986, No. 1, p. 20)
- 6. What are the shortcomings of community programs? How can these problems be addressed?
 - Some special construction may be necessary to accommodate people who are nonambulatory. (Links, January 1986, No. 1, p. 20)

Essential Components of Medicaid Reform Page 3

7. What are the advantages of community programs?

The first ICF/MR payouts were made in 1973 and in eight years the number of certified beds grew from 29 thousand to 196 thousand. This was a major transformation involving a concurrent 28% reduction in the population of

state institutions. The number of certified beds has been declining since 1981. (Links, January 1986, No. 1, P. 21)

THE NEED FOR MEDICAID REFORM

Presented to:

Senator David Durenberger

Helen Darling

Mary Edwards

From:

Association for Retarded Citizens, Minnesota;
Department of Human Services, Mental Retardation Division;
Governor's Planning Council on Developmental
Disabilities, Minnesota State Planning Agency;
Legal Advocacy for Persons with Developmental Disabilities
Minnesota Association for Persons with Severe Handicaps;
United Cerebral Palsy, Inc.

December 18, 1986

HOW WILL QUALITY BE MONITORED?

- THE U.S. SENATE HELD JOINT HEARINGS ON APRIL 1-3, 1985, TO REVIEW LOWELL WEICKER'S REPORT ON THE "CARE OF MENTALLY DISABLED PERSONS" WHICH DOCUMENTED POOR QUALITY, ABUSE, LIFE THREATENING CONDITIONS, AND UNEXPLAINED DEATHS IN "HEAVILY REGULATED, LICENSED, AND CERTIFIED PUBLIC INSTITUTIONS" THROUGHOUT THE U.S. AS A RESULT, HCFA PLACED A NEW EMPHASIS ON "LOOK BEHIND" AUDITS.
- WE NEED EXTERNAL MONITORING THAT IS SEPARATE FROM STATE AGENCIES THAT ADMINISTER, FUND, LICENSE, OR CERTIFY SERVICES.
- QUALITY CAN BE MONITORED USING PRINCIPLES SUCH AS AGE-APPROPRIATENESS, FUNCTIONAL SKILLS, AND COMMUNITY REFER ENCE ENVIRONMENTS.
- BY SUPPORTING PEOPLE WITH DISABILITIES IN REGULAR SETTINGS IN HOME COMMUNITIES, THERE IS GREATER SCRUTINY. INFORMAL SUPPORTS CAN PROVIDE ANOTHER MEANS OF MONITORING.
- EXISTING PROTECTIVE SERVICES CAN ALSO BE USED WHEN INDI VIDUALS ARE PART OF FAMILIES.

THE REAL ISSUE IS TO REDIRECT MEDICAID TO DEVELOP A COMMUNITY SYSTEM THAT NOT ONLY ADDRESSES RESIDENTS WHO SHOULD LEAVE STATE INSTITUTIONS AS WELL AS THOSE PEOPLE WHO ARE NOT SERVED OR INADEQUATELY SERVED IN COMMUNITY SETTINGS.

WHAT IS THE FINANCIAL IMPACT OF PHASING OUT INSTITUTIONAL CAKE AND DEVELOPMENT OF COMMUNITY AND INDIVIDUAL ALTERNATIVES?

- THE TRENDS IN EXPENDITURES ARE PRESENTED IN GRAPH FORM. BY NOT PHASING OUT INSTITUTIONAL CARE, THE PER DIEMS OF RE-GIONAL CENTERS COULD DOUBLE FROM \$159 PER DAY TO OVER \$3 00 PER DAY IN THE NEXT SEVERAL YEARS IF NO CHANGES OCCUR IN STAFFING/FIXED COSTS. (SEE FIGURE 1.)
- FUNDING HAS TO BE TARGETED TO MEET INDIVIDUAL NEEDS RATHER THAN TREATING ALL PEOPLE ALIKE. CURRENTLY, MEDICAID IS NOT AN EFFICIENT PROGRAM BECAUSE INDIVIDUALS RECEIVE TOO MUCH SERVICE OR TOO LITTLE SERVICE. THE OPTIONS ARE LIM ITED TO ICF-MR FACILITIES (24 HOURS OF CARE) OR LIMITED WAIVER SLOTS.
- MEDICAID PROFESSIONALIZES SERVICES AND FAILS TO TAKE AD VANTAGE OF GENERIC AGENCIES (PARKS, CHURCHES, RECREATION).
- MEDICAID DOES NOT ENCOURAGE MOVEMENT OUT OF THE SERVICE SYSTEM. MEDICAID DOES NOT ENCOURAGE INDIVIDUAL GROWTH.
- ALL COST STUDIES CONCLUDE THAT THE COST OF HOME AND COMMUNITY SERVICES IS EQUAL TO OR LESS THAN THE COST OF CONGREGATE CARE AND INSTITUTIONAL SERVICES. THERE ARE NO DATA TO SUPPORT THE NOTION THAT BIGGER IS CHEAPER SINCE COSTS ARE RELATED TO STAFFING, LEVEL OF INDIVIDUAL NEED, AND SERVICES PROVIDED.
- IN MINNESOTA, SEVERAL COMMUNITY ICF-MR PROVIDERS HAVE AL READY OR ARE PLANNING TO VOLUNTARILY DECERTIFY BEDS IN THEIR FACILITIES. FURTHER DECERTIFICATION SHOULD BE EN COURAGED.

WHAT ARE THE ESSENTIAL COMPONENTS OF MEDICAID REFORM?

- MEDICAID REFORM WOULD REMOVE THE INSTITUTIONAL BIAS OF MEDICAID. MEDICAID HAS HISTORICALLY FUNDED SPECIALIZED BUILDINGS, REFORMING MEDICAID MEANS SHIFTING FUNDING FROM BUILDINGS TO SERVICES (CITIZEN'S LEAGUE, 1984).
- MEDICAID REFORM WOULD SUPPORT NOT SUPPLANT THE FAMILY AND INFORMAL SUPPORT NETWORK. MEDICAID IS CURRENTLY A POWERFUL INCENTIVE FOR OUT-OF-HOME PLACEMENT.
- A STABLE SOURCE OF FUNDING IS NEEDED TO SUPPORT FAMILIES, SUPPORT INDIVIDUALIZED LIVING ARRANGEMENTS, AND PROVIDE AN ARRAY OF SERVICES USING EXISTING HOUSING AND SPACE. WE NEED A LONG-TERM COMMITMENT FOR COMMUNITY SERVICES THAT OFFERS CONTINUITY AND STABILITY FOR PEOPLE WITH LONG-TERM NEEDS.
- STATE INSTITUTIONS WILL BE PHASED OUT EVENTUALLY. MINNE-SOTA HAS 1,700 PEOPLE TODAY IN SEVEN REGIONAL CENTERS. IF THE RATE OF DEPOPULATION OF 200 RESIDENTS PER YEAR CONTIN-UES, THERE WOULD BE NO ONE LIVING IN REGIONAL CENTERS IN LESS THAN TEN YEARS.
- WE NEED TO FACE THE TOUGH ISSUES OF PHASEOUTS OF INSTITU TIONS: STAFF DISLOCATION (EMPLOYEE ISSUES), ECONOMIC IM PACT OF LOCAL COMMUNITIES, AND VACANT BUILDINGS.
- MEDICAID REFORM SHOULD GIVE PREFERENCE TO SUPPORTING PEO PLE WITH DEVELOPMENTAL DISABILITIES IN EMPLOYMENT SETTINGS RATHER THAN CONTINUING DAY ACTIVITY PROGRAMS THAT EMPHA SIZE SEGREGATED, NONFUNCTIONAL ACTIVITIES.
- EACH STATE WOULD BE RESPONSIBLE TO DEVELOP A MEDICAID PLAN THAT PROVIDES FOR ESSENTIAL COMPONENTS TO PROTECT INDIVIDUALS SUCH AS A MANDATED INDIVIDUAL PLAN, CASE MANAGEMENT, TRAINING, CRISIS INTERVENTION, AND SAFEGUARDS AGAINST ABUSE AND NEGLECT.

WHY IS MEDICAID REFORM NECESSARY?

MEDICAID IS INCONSISTENT WITH SOCIETAL VALUES OF BECOMING SELF-SUFFICIENT, PRODUCTIVE, AND MORE INDEPENDENT.

- MEDICAID EXPENDITURES HAVE RISEN AT A RAPID RATE AND ARE CURRENTLY THE EQUIVALENT OF THE FOURTH LARGEST U.S. CORPO RATION. MOBIL OIL IS THIRD LARGEST, AND FORD MOTOR COM PANY IS FIFTH LARGEST. THIS DRAMATIC GROWTH HAS OCCURRED BECAUSE OF UTILIZATION, ADDITIONAL ELIGIBLE POPULATION GROUPS, AND INFLATION. ONE OF THE FASTEST GROWING COMPO NENTS HAS BEEN LONG-TERM CARE FOR PEOPLE WITH DEVELOPMEN TAL DISABILITIES (ICF-MR FACILITIES) WHICH HAS INCREASED FROM \$70 MILLION IN 1972 TO OVER \$6 BILLION TODAY.
- FEDERAL POLICY HAS EMPHASIZED COMMUNITY PROGRAMS SINCE PRESIDENT KENNEDY'S PROCLAMATION IN 1963. YET FEDERAL FUNDING HAS CONTINUED TO BE BIASED TOWARD INSTITUTIONS (ICF-MR FACILITIES). EVEN AS THE POPULATION OF STATE INSTITUTIONS HAS DECLINED FROM 195,000 IN 1967 TO LESS THAN 100,000 TODAY, FEDERAL FUNDS FOR INSTITUTIONS HAVE CONTINUED TO DRAMATICALLY INCREASE. SEVENTY-FIVE PERCENT OF ALL ICF-MR FUNDS STILL GO TO STATE INSTITUTIONS. FUNDING DOES NOT MATCH POLICY. FUNDING DOES NOT FOLLOW CLIENTS.
- RESEARCH HAS CONCLUDED THAT INSTITUTIONS PERPETUATE DEPERSONALIZATION, LACK OF RESPECT, LACK OF DIGNITY, AND VULNERABILITY TO ABUSE. INCREASED FUNDING CAN NEVER ADDRESS THESE ENDEMIC PROBLEMS.
- ENVIRONMENTS HAVE PROFOUND EFFECTS ON PEOPLE WITH DISABIL ITIES. RECENT LONGITUDICAL RESEARCH INDICATES THAT THE GREATEST GAINS MADE BY PEOPLE WHO LEAVE INSTITUTIONS ARE THOSE WHO ARE THE MOST SEVERELY DISABLED. PEOPLE ACQUIRE MORE SKILLS IN SMALL, COMMUNITY SETTINGS THAN IN LARGE CONGREGATE CARE.
- RESIDENTS ARE NOT LEAVING INSTITUTIONS AS QUICKLY AS THEY SHOULD BECAUSE FUNDING HAS NOT SHIFTED TO COMMUNITY SERVICES. RESIDENTS OFTEN LEAVE BECAUSE OF LITIGATION.

WHO DO WE REPRESENT?

Association for Retarded Citizens of Minnesota (ARC) is one of the oldest and largest parent advocacy groups in the state with over 8,000 members. Founded in 1950, the ARC has been the leader in the state and nation for necessary reforms in education, residential services, habilitation, and rehabilitation.

Contact: Betty Hubbard, President; and/or Sue Abderholden, Associate Director; telephone: (612) 827-5641.

Department of Human Services. Mental Retardation Division is the single point in state government responsible for the administration of community services for over 15,000 people with mental retardation or related conditions. The current leadership strongly advocates for support to families, supported living (use of regular housing with necessary accommodation) and supported employment (paid work at regular work sites with ongoing staff support as needed).

Contact: Ed Skarnulis; telephone: (612) 296-2160.

The Governor's Planning Council on Developmental Disabilities is located in the State Planning Agency and receives federal funding for the planning, coordination, and monitoring of services to people with developmental disabilities. The Council represents a wide range of constituencies with over 60,000 people estimated to be developmentally disabled. The Council has completed extensive policy research and analysis on topics related to deinstitutionalization.

Contact: Colleen Wieck, telephone: (612) 296-9964.

Legal Advocacy for Persons with Developmental Disabilities is part of the Minneapolis Legal Aid Society and has been designated by the Governor to provide protection and advocacy services to over 60,000 people estimated to be developmentally disabled. Legal Advocacy has served as plaintiff attorneys for the Welsch case since 1972. Legal Advocacy handles all types of cases in education, case management, day programs, guardianship, and rehabilitation.

Contact: Anne Henry; telephone: (612) 332-7301.

The Minnesota Association for Persons with Severe Handicaps (MNASH) is a parent and professional organization representing thousands of people in Minnesota with the most severe handicaps. MNASH strongly supports integration of all people with disabilities in regular schools, regular housing, and regular employment. MNASH is currently working on an "Integration Imperative."

Contact: Toni Lippert; telephone: (612) 291-6364.

1822 "K" Street, NW Suite 1112 Washington DC 20005 202.842.4266

December 24, 1986



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MEMORANDUM

To: Memk

Members of the Medicaid Task Force and Selected Others

From: Allan I. Bergman

allan

Re: QUALITY ASSURANCE PRINCIPLES

In reviewing my notes, we have yet to develop principles for our document in the area of quality assurance. During a recent discussion with Jim Conroy, I raised the issue and he has sent me the attached document. I also discussed the issue with Colleen Weick who sent the attached list. There is a great deal of similarity between the two!

I trust you will have a chance to review these materials before our next meeting on January 7th. They were useful to me in conceptualizing the issue.

Best wishes for the holiday season and a Happy New Year!!

AIB/cc

Enclosures (2)

GFORGES, DOCING Vice Charanton MARTIN RUBENSTEIN President

WILLIAM BURENBERG, MD View President Medical Affans IAMEN INTROM

> MICHAEL W. MORRES Director

Executive

Minnesota Governor's Planning Council on Developmental Disabilities

DEVELOPMENTAL DISABILITIES PROGRAM, STATE PLANNING AGENCY 201 CAPITOL SQUARE BLDG. • 550 CEDAR STREET • ST. PAUL, MN 55101 • 612-296-4018

December 30, 1986

TO: Ed Skarnulis
Toni Lippert
Betty Hubbard
Anne Henry
Colleen Wilson

FROM: Colleen Wieck

Executive Director

REGARDING: Medicaid Reform Team

Here is the latest mailing from Allan Bergman, United Cerebral Palsy, regarding quality issues on Medicaid reform. If you have some ideas on quality assurance, please let me know or contact Allan directly.

I will talk to Allan on January 5, 1987, regarding the compromise language about phasedown.

cw/amc

Attachment

Minnesota Governor's Planning Council on Developmental Disabilities

DEVELOPMENTAL DISABILITIES PROGRAM, STATE PLANNING AGENCY 201 CAPITOL SQUARE BLDG • 550 CEDAR STREET • ST. PAUL, MN 55101 • 612-296-4018

December 15, 1986

Mr. Allan I. Bergman, Deputy Director United Cerebral Palsy Associations, Inc. Governmental Activities Office 1522 "K" Street, Northwest, Suite 1112 Washington, DC 20005

Dear Allan:

Here are some ideas regarding quality principles in Medicaid Reform:

- 1. Can we use the terms "quality of life" rather than "quality of care"?
- 2. can we mandate the use of observation of the individual as part of quality of life monitoring?
- 3. Can we use outcomes such as "independence," "productivity," and "integration" into the community?
- 4. Can we mention service principles such as ageappropriate, functional, community referenced, and the need for interaction with nonhandicapped peers?
- 5. Can we require independent verification of out comes at the state level by an agency that does not administer, fund, or certify the services?

Hope this helps.

Cordially,

Colleen Wieck, Ph.D. Executive Director

CW/amc



DRAFT #3

Principles of Quality Assurance: Recommendations for Action in Pennsylvania

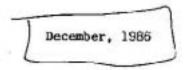
By:

James W. Conroy Director of Research & Program Evaluation

Celia S. Feinstein Director of Monitoring & Quality Assurance

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Introduction

This paper describes the properties of an "ideal" Quality Assurance system, and leads toward recommendations for immediate and practical action. We describe the ideal so that we will have something to aim toward, even though we can never reach it.

Values are deeply involved in all of the comments here- They will be stated clearly in the first section, in the form of 10 "principles" of Quality Assurance. In the second section, we describe the levels at which Quality Assurance activities are (or should be) conducted. Finally, in the third section, we make practical recommendations. The paper draws upon the experience of the Temple University Evaluation & Research Group, from 11 years of quantitative tracking and checking on the well-being of people in community service settings. Our Quality Assurance activities have included measurement of developmental growth patterns among people at Woodhaven Center, implementation of an outcome data system at the Woods Schools, creating a Quality Assurance system for the Special Master in the Gary W. case in Louisiana, designing and implementing Quality Assurance systems for deinstitutionalization efforts in Connecticut and New Hampshire, and tracking the Pennhurst classmembers since 1978 (in 1986, we will visit 980 classmembers in their community residences).

Our Pennsylvania work is included as a model system in the book

Assessing and Enhancing the Quality of Services: A Guide for the Human

Services Field, by Valerie Bradley et al. (Human Services Research

Institute, Cambridge, 1984). We have also met requests for consultation
and technical assistance on Quality Assurance in Arizona, California,

Colorado, Maryland, Michigan, Minnesota, New Mexico, New York, North Carolina, Texas, Virginia, Washington D.C., and several provinces of Canada.

In all regions, the central question seems to be the sane: How can we monitor and assure decent conditions in settings that are scattered all over the area?

Because of our experience in these areas, and because of our special commitment to the Pennsylvania service system, we are setting forth some of the conclusions we have reached about Quality Assurance. The paper is presented as input to the special committee on Quality Assurance that has been instituted by the Office of Mental Retardation (and to other interested parties). The recent position paper issued by that committee indicates that a set of specific proposals might stimulate concrete discussions and recommendations for action.

Because of the Governor's budget request, we believe this is a pivotal time for action in the Quality Assurance ares. This kind of atmosphere and funding may not appear again for many years. It is therefore essential that we get very specific about what we need to do, and it is imperative that we do so as soon as possible. Although our recommendations in their present form may not be adopted, we hope that they will spur the committee toward rapid and concrete resolutions about the desired structure of Quality Assurance in our system.

Principles

Because this paper comes from an agency that *is* directly involved in Quality Assurance activities in Pennsylvania, it is important to state our fundamental assumptions and values at the outset. The recommendations that we will offer would have some bearing on our own activities, and therefore we must be completely candid about our motivations, assumptions, and biases.

Principle 1: Quality Assurance Doesn't

Given the limitations of our service system (or any service system), no "Quality Assurance System" can really assure that high quality services are always delivered to every person. By itself, no such system is sufficient; there are other factors that are necessary. For example, in a system in which the average case manager's caseload is over 100 individuals, or in which there is little or no value-based training, or in which required training is only on-the-job or extremely brief, or in which the salaries of the direct care personnel are abysmally low and turnover is very high, no "Quality Assurance System" can guarantee what the term implies.

(None of these factors can assure quality by itself. In logical terms, all of the factors arc necessary, but none are sufficient.)

Within that context, however, it is *still* necessary to design a system to monitor the well—being of people in the service system. The monitoring activity is useful, even though it provides no *guarantee* of quality, because it identifies problems in peoples' lives (many of which are resolved after they are revealed), and because it also provides hard

information for officials who must decide on changes in resources and policies. With a decent monitoring system, which includes input from families and consumers themselves, there are also other direct benefits that can accrue to the implementers and supporters of the system.

Principle 2: Quality Assurance Occurs at Multiple Levels.

Quality assurance occurs at many levels of the service system. Part of what a CLA Project Director does is "assuring quality" by checking on the activities of direct care personnel, part of what a case manager does is Quality Assurance, and part of the contract negotiation process involves Quality Assurance (in that rates are, to some degree, set with one type and amount of services needed by people in mind). Because the term has many interpretations, and it is operative at all levels of the system, any successful statewide initiative in this area must select a clear and limited focus. Otherwise, the initiative is Likely to dissipate in an effort to satisfy needs at all levels.

Principle 3: Emphasize a Scientific Approach

The Quality Assurance activity must be presented and operated as a scientific enterprise. We must take as a given that no two observers can completely agree on the definition of "quality" in a community program; it follows that we are engaged in a continual process of collecting information that will teach us more and more about what factors contribute to a quality program, and how to measure those factors. Our position is that, unless we use the simple precepts of the scientific method, we will fail to learn as we go. And Quality Assurance is inherently a learning process.

Principle 4: Reliability Essential

If a monitor visits a CIA on day 1 and finds deficiencies A, B, and C, and another monitor visits on day 2 and finds deficiencies X, Y, and Z, then the CLA provider is certain to become cynical about the Quality Assurance activity. There is no "interrater reliability." The success of the provider is reduced to pure luck - the monitor that is assigned to the CLA may be an "easy grader," in which case the CLA will do well, or vice versa. The provider comes to view this unreliable monitoring as being completely unrelated to the "real" quality of the CLA setting.

If the providers do become cynical, and grow to treat the Quality Assurance as a "game" in which the goal is to "fool" the monitors, then the activity becomes useless. (Incidentally, in our view, this is one of the greatest weaknesses in all of the extant systems of facility standards such as CARF, ACMRDD, and ICFMR — none of them have ever been tested for reliability.)

Principle ST Focus on Individuals

We have already stated our belief that Quality Assurance occurs at all levels of the service system, but we also believe that the most important level is that of the individual. The Quality Assurance approaches that involve direct contact with the people we serve are the ones that we value the most. Within this principle, we place our conviction that Quality Assurance must maximize the involvement and input from consumers and from their most significant "others."

Also within this principle is subsumed the corollary that individually-oriented monitoring of decentralized community systems is

feasible end cost-effective. The idea of evaluating every person's situation every year might seem to be prohibitively costly, but this is not so. In our Pennsylvania activities, which include environmental assessments, plus family surveys, plus quantitative individual data on behavior, services, health, and day program, our costs have never exceeded \$250 per person per year. This has held true in other states as well.



Principle 6: Outcome Orientation

In our thinking, we tend to emphasize the fact that all people can grow and learn; we perceive the central goal of our efforts to be to maximize individual potential. This means assisting people toward continually increasing abilities/skills, and away from maladaptive behaviors. These changes can be measured effectively and reliably, and our position is that no Quality Assurance system is complete (or even adequate) until it can demonstrate that service recipients are showing measurable gains.

However, the notion of outcome is not limited to growth; outcome includes the *outcome* of individual happiness and comfort plus the *outcome* of family satisfaction plus the *outcome* of increased acceptance, status, and integration within our society. All of these outcomes must be measured; if they cannot be measured, then they must be subjected to *attempts* to measure, so that someday we can scientifically determine changes in any of them. These concrete changes in individual lives should be the ultimate unit of service accountability.

Principle 7: Seep Monitoring and Followup Separate

The collection of reliable information about the quality of people's lives (usually called monitoring, from the Latin word monere, meaning 'to warn') is only half of the Quality Assurance loop. The second half is doing something about what we find. We believe the "followup" function (also called compliance or enforcement) should be entirely separate from the monitoring. Monitors should seek the facts and report them, and followup personnel (enforcers) should check the veracity of those reports, and demand corrections where appropriate. If we allow the monitors to follow up on the corrections of the situations they have found, then they will be unduly motivated to "prove" that their initial observations were correct. It is better to divide the functions clearly, so that, when the inevitable errors and miscommunications occur, the followup personnel will not be personally invested in righting a wrong that does not exist.

Principle 8: Seep Monitoring Independent

Ideally, the monitoring activity should be absolutely free of vested interests and biases; monitors should be interested *only* in ascertaining the *truth* about people's situations, and not with what they think should be done about it, nor with the feasibility of remedies. This leads to the conclusion that the monitoring function is best located within an independent third party entity that has no particular axe to grind. (This is the area in which our own conflict of interest exists — because we are an independent third party, this

recommendation tends to benefit our own agency. This should be taken into account in evaluating our advocacy of this idea.)

Principle 9: Followup Function Needs "Clout"

Ideally, the monitoring activity should be carried out by a neutral third party, and the followup activity should be carried out by an entity with "clout". In order to demand that a situation be corrected, or to reward a program for an admirable job, the followup personnel must have great power — and power in this service system usually means control over money. The followup function should therefore be placed within the agency that has the most powerful "clout".

In Pennsylvania, the county has fiscal authority over providers, but is limited in the actions it can take because the county is, in turn, dependent upon state government for the base allocation. The fact is that the greatest degree of "clout" exists at the state level. It follows that the followup function should be conceptually (but not necessarily geographically) centralized at the state agency level, and that the followup entity should have no other jobs - it should focus on just one thing, which is to receive information about the situations of consumers and act on it.

Principle 10: Followup Includes Rewards

We maintain that the ideal Quality Assurance system will deliver not just threats and penalties for bad conditions, but also rewards for good performance. Moreover, for the situation in which a needed service is not being delivered because of a lack of funds, the system must not penalize the program by taking away more funds. Instead, there must be a way to reward good performance, punish inexcusably bad performance, and to help direct funds to areas of bad performance where money is the reason for the bad performance. (In an ideal world, the enforcers would find themselves delivering more rewards than punishments.)

Levels of Monitoring

Quality Assurance can be divided into two essential parts. The first part is the fact-finding function, called monitoring. The word monitoring is derived from a Latin word that means to give warning. The monitoring function is a warning function. The second part of Quality Assurance is that some agency must act on those warnings. We refer to this function as "followup" or "enforcement."

Both the monitoring and the followup function occur at all levels of the service system. In this section, we describe the multiple levels of monitoring, most of which already exist to some degree in Pennsylvania's community service system,

The way we categorize the levels of monitoring, there are 12 levels: county plans, fiscal monitoring, licensing, recognized standards, quantitative environmental assessment scales, case management, parent/sibling/advocate monitoring, independent IHP review, IHP based monitoring, individual quantitative outcome oriented monitoring, family surveys, and individual interviews. This list proceeds from the farthest removed to the closest to the people served. Next, we describe briefly what Quality Assurance activities happen at each level.

County Plans

The mechanism by which the state OMR collects facts about the situations in the counties (very distant from the people served, people are never mentioned as individuals).

Fiscal Monitoring

After counties contract with providers, they track the expenditures of the providers through mechanisms specific to each county.

Licensing

This is a minimalist approach to Quality Assurance, and, in Pennsylvania's CLA system, the licensing standards are basic, they are oriented toward the physical plant to a large degree, and only about half of each provider's sites are visited each year. Pennsylvania's licensing standards were developed in-house.

Recognized Standards

These include ACMRDD, CARF, and ICFMR standards. They are presumably more valid than locally developed licensing standards, because so much more effort has gone into them. Each claims to focus on individuals, but the bulk of standards items in them are concerned with safety, management practices, physical plant, rules, and procedures. These approaches assume that, if a facility gets a high score on the standards, then the people who live or work there will experience a high quality of life, including continual growth and development. (We can see little need for this assumption, because accurate measurement of developmental growth for every individual is so simple and inexpensive.) None of these standards has ever published any study of interrater or other reliability.

These standards, like licensing, have an important role to play in assuring that settings meet the most basic requirements of health and safety, and that they follow accepted programming practices. By themselves, however, the recognized standards will assure that quality is at least minimal, but will not assure *high* quality.

Quantitative Environmental Assessment Scales

These instruments are attempts to quantify the qualities of the environments in which people live and work. Some of the best known are: the Resident Management Practices Inventory (developed by King, Raynes, & Tizard in England, then used cross-culturally by Balla & Zigler, and later adapted for use in the Pennhurst Longitudinal Study), which is a measure of aspects of individualization versus regimentation; Program Analysis of Service Systems (by Wolfensberger & Glenn), a measure of aspects of normalization; and the MEAP rating scale for the physical plant aspects (pleasant, clean, homelike) of the setting.

These scales, particularly the value-baaed ones like PASS, have an educational function that can be very important; however, the degree of reliability that has been established for them is not yet high enough to justify their use on anything but an experimental basis. Experimental and scientific inquiry should continue, but no such instrument is ready for making funding decisions.

(Although training may be a separate issue from the Quality Assurance discussion, it seems worth pointing out that value-based training may be a crucial precondition for high quality programs. There is little activity in this area in Pennsylvania.)

Case Management

Case managers fulfill several essential Quality Assurance functions during the routine conduct of their duties. Case management is potentially the most important bridge among the many levels of Quality Assurance in the current community service system.

The case manager should be able to get to know the people on his/her caseload, and should visit every person every month. The case manager helps design the IHP, and should be checking to see that it is implemented properly. The case manager should be able to visit a site and make recommendations about integration, contact with neighbors, the physical plant, procedures, safety, and cleanliness. All in all. the case manager is not directly paid to deliver care, but rather to assure that quality services are being delivered.

Two serious problems in the case management function remain. Right now, with caseloads averaging over 100, and case managers being entirely absent in some county systems, the case management function is fatally hindered. Also, the case managers in many county systems are almost completely lacking in "clout", and/or they are placed in a structural position of conflict of interest (getting a paycheck from the same agency that is delivering some of the services). Thus all the shoulds in the paragraph above are currently unrealistic. Unless the case management system is strengthened, it would be counterproductive to demand any more Quality Assurance activity at the case management level.

Parent/Sibling/Advocate Monitoring

A different kind of monitoring can be conducted by parents and "significant others." According to the original article describing such a function, (Provencal, G. & Taylor, R. (1983). Security for parents: Monitoring of group homes by consumers. *The Exceptional Parent*, 13, p. 39-46.

... there is an important oversight role to be played by the "candid consumer. And when encouraged, this role can lead to improved programs which parents may come to trust more fully ... Monitors do not visit homes where their relatives or wards reside ... Visits are made approximately every 2 months ... The monitor's primary responsibility is to evaluate the "feel" of each home; its appearance, atmosphere, warmth and overall sensitivity to ... the resident's well-being. Quite deliberately, monitors do not assess individual client programs, procedure compliance, or performance toward standards that are to be reviewed by other agencies.

These monitors apparently tend to identify a variety of issues that are missed at all other levels. Presently, Pennsylvania has no major commitment to this kind of monitoring.

Independent IHP Review

Under the Pennhurst court order we saw the first implementation of a peer review system for IHPs. The plans developed by the interdisciplinary teams were submitted to the Special Master for review, and the Special Master could demand changes. Later, this function was moved to the Special Management Unit. More recently, this function has either moved to the county level or it has been abandoned. It seems clear that review by a qualified professional, trained in program planning and task analysis, would help to reduce the frequency of IUPs that are completely inadequate and inappropriate (of which all of us, no doubt, have seen several examples)-

IHP Based Monitoring

This activity is individually oriented. The monitor attempts to determine whether everything in the IHP is being addressed, and whether the services are appropriate and adequate. This is the original orientation taken by the Special Management Unit. The approach may be somewhat subjective, unless clear and reliable guidelines can be established to define "adequate" services, but it does seem to be an extremely useful method for assuring accountability. If performed by a separate entity, as in the SMU case, this activity serves as a backup and double-check for the case manager, who should be doing the same thing on a regular basis.

Individual Quantitative Outcome Oriented Monitoring In this approach, instruments that are standardized and tested and reliable are collected for every individual. The data are collected by interviewing direct core and other staff, particularly the staff who know each consumer the beat, plus records scrutiny. This level of Quality Assurance permits evaluation of behavioral growth, as well as of changes in program goals and service delivery patterns. Because the data are quantitative, they can be aggregated across programs or counties, in order to find pervasive patterns of excellence or of shortcomings; and the performance of providers and of counties can be compared.

This kind of system includes a "Red Flag" component, in which certain situations are defined by consensus as unacceptable. In the most extreme case, such as the detection of evidence of abuse or neglect, the system requires notification of state officials within 24 hours of the monitoring. In less extreme cases, such as failure to perform a routine audiological, notification of the state is within 30 days and the followup might be a phone call. The system includes a "Green Flag" component as well, for significant individual development, for settings in which there are no problem situations, and so forth. (This is the level at which the Temple Quality Assurance activities occur. Therefore our comments must be weighed accordingly.)

Family Surveys

Every year, every person's most significant "other" is surveyed by moil about the perceived well-being of the person. The survey can be a single sheet of paper, completed in 5 minutes, and provides an avenue

for expression of satisfaction and/or concerns. We believe the cost-effectiveness of this monitoring activity is the highest of all. Each survey, even after analysis and reporting, costs only a few dollars; but the data provide one of the most sensitive indicators of overall satisfaction with the system, as well as providing one of the only avenues for officials to receive *good* news.

Moreover, the data enable the enforcement branch of Quality Assurance to look directly into situations in which a family expresses extreme dissatisfaction. Such situations should not be ignored, and it seems wise to assure that such situations reach the highest level possible, much higher, for example, than the CLA direct care staff or project director. Because it is difficult for families to negotiate the system and to reach the "higher-ups" who can do something about their concerns, the survey is a welcome innovation for families.

Individual Interviews

We believe that every person capable of verbal or signing interaction should be interviewed about their own feelings, if they so choose. These interviews, if they are treated with appropriate caution (include redundant questions and tests for acquiescence) can be treated as important and useful date. Extreme and reliable unhappiness should, for example, be treated as a Red Flag; it should call in a special review of the situation by the follow up branch. (An interesting recent development is the use of consumers to interview consumers.)

Followup/Enforcement & Assistance Mechanisms

Again, these comments will outline what we perceive to be the "ideal" in the area of followup/enforcement and assistance- Such a function would ideally be situated at the state government level, for reasons stated previously, i.e., in our system, that is where the buck, and we do mean money, stops.

The ideal system would include a new division in the Office of Mental Retardation, with an employee for each unit of the state; in this case, each unit would cover no more than 150 people in community services. The jurisdictions could be combined where they are small, and divided where they are very large (Pittsburgh and Philadelphia would require at least two followup personnel each). The physical location of the followup personnel would be decentralized, and, to the extent possible, would take advantage of existing space available to the state.

The only function of these people would be to receive monitoring information about the situations of consumers and act on it. The information would come from all levels of the monitoring function, but would concentrate on IHP monitoring, individual quantitative monitoring, family surveys, and individual interviews. On occasion, the followup personnel would take action on reports from parent monitors or from case managers.

The followup personnel would, in our ideal system, be accorded unprecedented powers (that is, unprecedented in Pennsylvania - what we are proposing here is actually very close to the level of power of the "broker-advocates" in the Service Integration for Deinstitutionalization

project in Virginia in the late sixties). Because of the ultimate necessity for Quality Assurance to be related to money, the followup personnel would have the authority to make a very strong recommendation to the Deputy Secretary to make adjustments — in either direction — to the base allocation of a given jurisdiction.

In the case of a remedy demanded, but none forthcoming and no reason given, the recommendation would be for a subsequent year reduction in the allocation to that county or multi-county jurisdiction. The exact amounts of these "penalties" would be placed in categories according to the severity of the "red flag." In the case of a remedy demanded, but none forthcoming, and with clear evidence that a shortage of funds is at fault, the recommendation could be for an increase of exactly the amount needed for the subsequent allocation. In the case of a remedy demanded, and provided, no action would be necessary. (When allocations are reduced, and there is a dispute about the facts of the situation, an appeal/hearing/arbitration mechanism before a designee of the Deputy Secretary would be necessary.)

In many cases, we would expect to see a problem situation for which the remedy would be a certain kind of training that is not currently available to the provider, or for which the provider (and the county) cannot pay. At the discretion of the followup personnel, funds would ideally be available in limited quantities for special emergency training of this sort. The followup person could then authorize and pay for immediate assistance of the sort that is now often provided by core teams; but where the core team lacks the expertise needed, the county cannot pay, and there is no extra money in the provider's budget.

Therefore a central capability is essential, particularly for the many counties in which there is no core team and most programs have no budgeted amount for such contingencies. In most cases, we would expect the cost of these emergency training interventions to be remarkably small, but they would pay off in very high ratios for the well-being of people and programs. In some cases, it is to be hoped that central office training personnel could impart the training directly.

Because of the power this scheme assigns to the followup personnel, it seems to us that a Procedures Manual would have to be written before the first enforcer was hired. It would change rapidly, of course, but the rules and limitations of the game would have to he made clear to prevent gross misjudgments and inconsistencies. The followup personnel would have to be very skilled and experienced, but certain guidelines would be necessary to keep consistency among them: what conditions trigger an unannounced site visit, what conditions justify a warning of a base allocation reduction, and so on.

Recommendations

Following the "pie-in-the-sky" notions in the preceding section, we present here what we think may be reasonably practical directions for the immediate future. We reiterate that no such system, no matter how elegant or radically powerful, can truly do what the phrase Quality Assurance implies by itself. Yet, in the direction of improving the chances of each individual we serve to avoid and/or escape from unpleasant and inappropriate situations, we offer the following concrete suggestions.

1) Strengthen Case Management

Case management is an essential part of the Quality Assurance loop, like it or not, and it is also one of the most important. No case manager should have a caseload of over 100, when a rich body of literature suggests a practical maximum of 30. The case manager should visit every person every month (or so), and this places an upper limit on the sensible caseload. At what other level of the system can we assure that a reasonably objective third party enters the community setting and checks up on conditions? The annual review level of monitoring is completely inadequate to safeguard against abuse and neglect. Someone must visit frequently.

This, it seems to us, is an extremely urgent and appropriate direction for a significant chunk of the proposed increase in the state budget. (We realize that the number of placements is likely to become the only yardstick for success, but, in this paper, we are constrained

to ignore that and to recommend what would improve *quality*, not quantity.)

Moreover, case managers should have a standardized training curriculum that is coordinated centrally. The tower of Babel currently in existence for case management training must be ended, and the only possible locus of leadership is the state office. We also urge that this training include and emphasize valued-based training, including normalization (or passing, or social role valorization). There is no reason for e case manager in this state to be ignorant of the issues raised by the ideologues.

2) Make a financial commitment to quantitative, individually oriented monitoring. (Again, this is the area of Temple's conflict of interest, so weigh our recommendations accordingly.) There is no reason, in our view, why one of the nation's leaders in community living cannot allocate less than \$250 per person per year to collect the annual individual growth data, plus the family survey data, plus the quantitative environmental scale data, that will help us demonstrate the beneficial effects of the legislature's funding. There are few stronger supports in that arena than reliable evidence that the recipients of service are growing, benefiting, and becoming progressively less dependent.

One approach in this direction might be to mandate that counties select or design their own systems of this kind of monitoring, but we believe that this strategy would result in far more confusion. In some areas, the state simply must take leadership, so that we can have some consistency across political boundaries.

- 3) Begin serious testing of the idea of a followup/enforcement division at the state level, including the idea of fiscal powers. This could begin with a jurisdiction that volunteers to try out such a system, but would have to be matched with a similar jurisdiction that did not volunteer. Somehow, we must eventually move in the direction of fiscal implications for failures to act, and for successful actions. In addition, more power should be placed in the hands of those who are closer to the problems, but who are not in a situation of conflict. This would be the advantage of the followup personnel at the state level. In a fallback strategy, the followup personnel, with all the powers outlined above, could be contracted for; this would avoid the near-impossibility of hiring so many new state employees. He do not know whether this would be as effective as using state employees.
- 4) Take steps toward eventual upgrading of the licensing process, including scientific teats of reliability, and probably moving toward one or more of the nationally recognized standards. There are many avenues of "self-survey" with occasional outside verification that are available from the organizations that promulgate those standards, and these methods might replace the current minimalist licensing approach at a minor increase in cost. Moreover, it might be possible to require at least a self-survey every year, and some would argue that this kind of internal program scrutiny is educational and valuable in itself.

We emphasize, however, our own perspective: this level of Quality Assurance is largely based on assumption and inference, with no known reliability. It is *possible* to look good on such standards by cleaning up the paperwork of a facility, by promulgating a few "policies" that

have no daily impact on life in the trenches, and so forth. By itself, this could be practically a zero contribution to Quality Assurance at the level of the consumers' daily lives,

- 5) Family surveys should be mandated annually for the entire state system of community services. They can be performed by mail, and for 6000 people in community services, such an effort would cost between \$120,000 and \$240,000 total each year, including red flag notifications. This is one of the only ways in which state officials can receive good news, and it is one of the only ways in which the concerns and fears of families are expressed.
- 6) Individual interviews should be required if Recommendation # 2 is implemented, and part of the effort should use consumers to interview consumers on an experimental basis.
- 7) Parent/Sibling/Advocate monitoring should be supported in the form of one or more pilot projects. In any given county, all that is needed is enough money to support one full-time professional and an assistant, plus office and some equipment, to generate and maintain a large workforce of monitors.
- 8) Independent IHP review mechanisms should be considered as a formal requirement, because so many problems arising from careless and just plain phony written plans could be headed off by such a mechanism.

1522 "K" Street NW Suite 1112 Washington DC 20005

December 24, 1986

allan



Board

DALK

Chairman

LEONARD IL

MEMORANDUM

To: Members of the Medicaid Task Force and Selected Others

From: Allan I. Bergman

Re: QUALITY ASSURANCE PRINCIPLES

In reviewing my notes, we have yet to develop principles for our document in the area of quality assurance. During a recent discussion with Jim Conroy, I raised the issue and he has sent me the attached document. I also discussed the issue with Colleen Weick who sent the attached list. There is a great deal of similarity between the two!

I trust you will have a chance to review these materials before our next meeting on January 7th. They were useful to me in conceptualizing the issue.

Best wishes for the holiday season and a Happy New Year!!

AIB/cc

Enclosures (2)

HAUSSIAN View Charmon. SINALAHOS Aww Chairman HOMARD C 201 20 11 110 Nice Chairman GEORGIA N DOUBLE Vice Charman MARLEN RUBE SSEEDS Prevalent TEXT PRESITATION President Elect WHITEAM BURLAND RG, MD President Medical Attairs JAMES. INTRONE Lacentine Director MICHAEL W. MORRIS Director



DRAFT #3

Principles of Quality Assurance:

Recommendations for Action in Pennsylvania

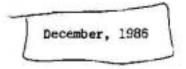
By;

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Minnesota Governor's Planning Council on Developmental Disabilities

DEVELOPMENTAL DISABILITIES PROGRAM. STATE PLANNING AGENCY

201 Capitol SQUARE BLDG. • 550 CEDAR STREET • ST, PAUL, MN 55101 • 612-296-4018

December 15, 1986

Mr. Allan I. Bergman, Deputy Director United Cerebral Palsy Associations, Inc. Governmental Activities Office 1522 "K" Street, Northwest, Suite 1112 Washington, DC 2 0005

Dear Allan;

Here are some ideas regarding quality principles in Medicaid Reform:

- Can we use the terms "quality of life" rather than "quality of care"?
- Can we mandate the use of observation of the individual as part of quality of life monitoring?
- Can we use outcomes such as "independence," "productivity," and "integration" into the community?
- Can we mention service principles such as ageappropriate, functional, community referenced, and the need for interaction with nonhandicapped peers?
- Can we require independent verification of out comes at the state level by an agency that does not administer, fund, or certify the services?

Hope this helps.

Cordially,

Colleen Wieck, Ph.D.

Executive Director

CW/amc

Introduction

This paper describes the properties of an "ideal" Quality Assurance system, and leads toward recommendations for immediate and practical action. We describe the ideal so that we will have something to aim toward, even though we can never reach it.

Values are deeply involved in all of the comments here. They will be stated clearly in the first section, in the form of 10 "principles" of Quality Assurance. In the second section, we describe the levels at which Quality Assurance activities are (or should be) conducted. Finally, in the third section, we make practical recommendations. The paper draws upon the experience of the Temple University Evaluation & Research Group, from 11 years of quantitative tracking and checking on the well-being of people in community service settings. Our Quality Assurance activities have included measurement of developmental growth patterns among people at Woodhaven Center, implementation of an outcome data system at the Woods Schools, creating a Quality Assurance system for the Special Master in the Gary W. case in Louisiana, designing and implementing Quality Assurance systems for deinstitutionalization efforts in Connecticut and New Hampshire, and tracking the Pennhurst classmembers since 1978 (in 1986, we will visit 980 classmembers in their community residences).

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and technical assistance on Quality Assurance in Arizona, California,

Colorado, Maryland, Michigan, Minnesota, New Mexico, New York, North Carolina, Texas, Virginia, Washington D.C., and several provinces of Canada.

In all regions, the central question seems to be the same: How can we monitor and assure decent conditions in settings that are scattered all over the area?

Because of our experience in these areas, and because of our special commitment to the Pennsylvania service system, we are setting forth some of the conclusions we have reached about Quality Assurance. The paper is presented as input to the special committee on Quality Assurance that has been instituted by the Office of Mental Retardation (and to other interested parties). The recent position paper issued by that committee indicates that a set of specific proposals night stimulate concrete discussions and recommendations for action.

Because of the Governor's budget request, we believe this is a pivotal time for action in the Quality Assurance area. This kind of atmosphere and funding may not appear again for many years. It is therefore essential that we get very specific about what we need to do, and it is imperative that we do so as soon as possible. Although our recommendations in their present form may not be adopted, we hope that they will spur the committee toward rapid and concrete resolutions about the desired structure of Quality Assurance in our system.

Principles

Because this paper comes from an agency that is directly involved in Quality Assurance activities in Pennsylvania, it is important to state our fundamental assumptions and values at the outset. The recommendations that we will offer would have some hearing on our own activities, and therefore we must be completely candid about our motivations, assumptions, and biases.

Principle 1: Quality Assurance Doesn't

Given the limitations of our service system (or any service system), no "Quality Assurance System" can really assure that high quality services are always delivered to every person. By itself, no such system is sufficient; there are other factors that are necessary. For example, in a system in which the average case manager's caseload is over 100 individuals, or in which there is little or no value-based training, or in which required training is only on-the-job or extremely brief, or in which the salaries of the direct care personnel are abysmally low and turnover is very high, no "Quality Assurance System" can guarantee what the term implies.

(None of these factors can assure quality by itself. In logical terms, all of the factors are necessary, but none are sufficient.)

Within that context, however, it is *still* necessary to design a system to monitor the well-being of people in the service system. The monitoring activity is useful, even though it provides no *guarantee* of quality, because it identifies problems in peoples' lives (many of which are resolved after they are revealed), and because it also provides hard

information for officials who must decide on changes in resources and policies. With a decent monitoring system, which includes input from families and consumers themselves, there are also other direct benefits that can accrue to the implementers and supporters of the system.

Principle 2: Quality Assurance Occurs at Multiple levels.

Quality assurance occurs at many levels of the service system. Part of what a CLA Project Director does is "assuring quality" by checking on the activities of direct care personnel, part of what a case manager does is Quality Assurance, and part of the contract negotiation process involves Quality Assurance (in that rates are, to some degree, set with the type and amount of services needed by people in mind). Because the term has many interpretations, and it is operative at all levels of the system, any successful statewide initiative in this area must select a clear and limited focus. Otherwise, the initiative is likely to dissipate in an effort to satisfy needs at all levels.

Principle 3: Emphasize a Scientific Approach

The Quality Assurance activity must be presented and operated as a scientific enterprise. We must take as a given that no two observers can completely agree on the definition of "quality" in a community program; it follows that we are engaged in a continual process of collecting information that will teach us more and more about what factors contribute to a quality program, and how to measure those factors. Our position is that, unless we use the simple precepts of the scientific method, we will fail to learn as we go. And Quality Assurance is inherently a learning process.

Principle 4: Reliability Essential

If a monitor visits a CLA on day 1 and finds deficiencies A, B, and C, and another monitor visits on day 2 and finds deficiencies X, Y, and Z, then the CLA provider is certain to become cynical about the Quality Assurance activity. There is no "interrater reliability." The success of the provider is reduced to pure luck - the monitor that is assigned to the CLA may be an "easy grader," in which case the CLA will do well, or vice versa. The provider comes to view this unreliable monitoring as being completely unrelated to the "real" quality of the CLA setting.

If the providers do become cynical, and grow to treat the Quality Assurance as a "game" in which the goal is to "fool" the monitors, then the activity becomes useless. (Incidentally, in our view, this is one of the greatest weaknesses in all of the extant systems of facility standards such as CARF, ACMRDD, and ICFMR — none of them have ever been tested for reliability.)

Principle 5: Focus on Individuals

We have already stated our belief that Quality Assurance occurs at all levels of the service system, but we also believe that the most important level is that of the individual. The Quality Assurance approaches that involve direct contact with the people we serve are the ones that we value the most. Within this principle, we place our conviction that Quality Assurance must maximize the involvement and input from consumers and from their most significant "others."

Also within this principle is subsumed the corollary that individually-oriented monitoring of decentralized community systems is

feasible and cost-effective. The idea of evaluating every person's situation every year night seem to be prohibitively costly, but this is not so. In our Pennsylvania activities, which include environmental assessments, plus family surveys, plus quantitative individual data on behavior, services, health, and day program, our costs have never exceeded \$250 per person per year. This has held true in other states as well.

*

Principle 6: Outcome Orientation

In our thinking, we tend to emphasize the fact that all people can grow and learn; we perceive the central goal of our efforts to be to maximize individual potential. This means assisting people toward continually increasing abilities/skills, and away from maladaptive behaviors. These changes can be measured effectively and reliably, and our position is that no Quality Assurance system is complete (or even adequate) until it can demonstrate that service recipients are showing measurable gains.

However, the notion of outcome is not limited to growth; outcome includes the *outcome* of individual happiness and comfort plus the *outcome* of family satisfaction plus the *outcome* of increased acceptance, status, and integration within our society. All of these outcomes must be measured; if they cannot be measured, then they must be subjected to *attempts* to measure, so that someday we can scientifically determine changes in any of them. These concrete changes in individual lives should be the ultimate unit of service accountability.

Principle 7: Keep Monitoring and Followup Separate

The collection of reliable information about the quality of people's lives (usually called monitoring, from the Latin word monere, meaning 'to warn') is only half of the Quality Assurance loop. The second half is doing something about what we find. He believe the "followup" function (also called compliance or enforcement) should be entirely separate from the monitoring. Monitors should seek the facts and report them, and followup personnel (enforcers) should check the veracity of those reports, and demand corrections where appropriate. If we allow the monitors to follow up on the corrections of the situations they have found, then they will be unduly motivated to "prove" that their initial observations were correct. It is better to divide the functions clearly, so that, when the inevitable errors and miscommunications occur, the followup personnel will not be personally invested in righting a wrong that does not exist.

Principle 8: Keep Monitoring Independent

Ideally, the monitoring activity should be absolutely free of vested interests and biases; monitors should be interested *only* in ascertaining the *truth* about people's situations, and not with what they think should be done about it, nor with the feasibility of remedies. This leads to the conclusion that the monitoring function is best located within an independent third party entity that has no particular axe to grind. (This is the area in which our own conflict of interest exists — because we are an independent third party, this

recommendation tends to benefit our own agency. This should be taken into account in evaluating our advocacy of this idea.)

Principle 9: Followup Function Needs "Clout"

Ideally, the monitoring activity should be carried out by a neutral third party, end the followup activity should be carried out by an entity with "clout". In order to demand that a situation be corrected, or to reward a program for an admirable job, the followup personnel must have great power — and power in this service system usually means control over money. The followup function should therefore be placed within the agency that has the most powerful "clout".

In Pennsylvania, the county has fiscal authority over providers, but is limited in the actions it can take because the county is, in turn, dependent upon state government for the base allocation. The fact is that the greatest degree of "clout" exists at the state level. It follows that the followup function should be conceptually (but not necessarily geographically) centralized at the state agency level, and that the followup entity should have no other Jobs - it should focus on just one thing, which is to receive information about the situations of consumers and act on it.

Principle 10: Followup Includes Rewards

We maintain that the ideal Quality Assurance system will deliver not just threats and penalties for bad conditions, but also rewards for good performance. Moreover, for the situation in which a needed service is not being delivered because of a lack of funds, the system must not penalize the program by taking away more funds. Instead, there must be a way to reward good performance, punish inexcusably bad performance, and to help direct funds to areas of bad performance where money is the reason for the bad performance. (In an ideal world, the enforcers would find themselves delivering more rewards than punishments.)

Levels of Monitoring

Quality Assurance can be divided into two essential parts. The first part is the fact-finding function, called monitoring. The word monitoring is derived from a Latin word that means to give warning. The monitoring function is a warning function. The second part of Quality Assurance is that some agency must act on those warnings. We refer to this function as "followup" or "enforcement."

Both the monitoring and the followup function occur at all levels of the service system. In this section, we describe the multiple levels of monitoring, most of which already exist to some degree in Pennsylvania's community service system.

The way we categorize the levels of monitoring, there are 12 levels; county plans, fiscal monitoring, licensing, recognized standards, quantitative environmental assessment scales, case management, parent/sibling/advocate monitoring, independent IHP review, IHP based monitoring, individual quantitative outcome oriented monitoring, family surveys, and individual interviews. This list proceeds from the farthest removed to the closest to the people served. Next, we describe briefly what Quality Assurance activities happen at each level.

County Plans

The mechanism by which the state OMR collects facts about the situations in the counties (very distant from the people served, people are never mentioned as individuals).

Fiscal Monitoring

After counties contract with providers, they track the expenditures of the providers through mechanisms specific to each county.

Licensing

This is a minimalist approach to Quality Assurance, and, in Pennsylvania's CLA system, the licensing standards are basic, they are oriented toward the physical plant to a large degree, and only about half of each provider's sites are visited each year. Pennsylvania's licensing standards were developed in-house.

Recognized Standards

These include ACMRDD, CARF, and ICFMR standards. They are presumably more valid than locally developed licensing standards, because so much more effort has gone into then. Each claims to focus on individuals, but the bulk of standards items in them are concerned with safety, management practices, physical plant, rules, and procedures. These approaches assume that, if a facility gets a high score on the standards, then the people who live or work -there will experience a high quality of life, including continual growth and development. (We can see little reed for this assumption, because accurate measurement of developmental growth for every individual is so simple and inexpensive.) None of these standards has ever published any study of interrater or other reliability.

These standards, like licensing, have an important role to play in assuring that settings meet the most basic requirements of health and safety, and that they follow accepted programming practices. By themselves, however, the recognized standards will assure that quality is at least minimal, but will not assure high quality.

Quantitative Environmental Assessment Scales

These instruments are attempts to quantify the qualities of the environments in which people live and work. Some of the best known are: the Resident Management Practices Inventory (developed by King, Raynes, & Tizard in England, then used cross-culturally by Bella & Zigler, and later adapted for use in the Pennhurst Longitudinal Study), which is a measure of aspects of individualization versus regimentation; Program Analysis of Service Systems (by Wolfensberger & Glenn), a measure of aspects of normalization; and the MEAP rating scale for the physical plant aspects (pleasant, clean, homelike) of the setting.

These scales, particularly the value-based ones like PASS, have an educational function that can be very important; however, the degree of reliability that has been established for them is not yet high enough to justify their use on anything but an experimental basis. Experimental and scientific inquiry should continue, but no such instrument is ready for making funding decisions.

(Although training may be a separate issue from the Quality Assurance discussion, it seems worth pointing out that value-based training may be a crucial precondition for high quality programs. There is little activity in this area in Pennsylvania.)

Case Management

Case managers fulfill several essential Quality Assurance functions during the routine conduct of their duties. Case management is potentially the most important bridge among the many levels of Quality Assurance in the current community service system.

The case manager should be able to get to know the people on his/her caseload, and should visit every person every month. The case manager helps design the IHP, and should be checking to see that it is implemented properly. The case manager should be able to visit a site and make recommendations about integration, contact with neighbors, the physical plant, procedures, safety, and cleanliness. All in all, the case manager is not directly paid to deliver care, but rather to assure that quality services are being delivered.

Two serious problems in the case management function remain. Right now, with caseloads averaging over 100, and case managers being entirely absent in some county systems, the case management function is fatally hindered. Also, the case managers in many county systems are almost completely lacking in "clout", and/or they are placed in a structural position of conflict of interest (getting a paycheck from the same agency that is delivering some of the services). Thus all the shoulds in the paragraph above are currently unrealistic. Unless the case management system is strengthened, it would be counterproductive to demand any more Quality Assurance activity at the case management level.

Parent/Sibling/Advocate Monitoring

A different kind of monitoring can be conducted by parents and "significant others." According to the original article describing such a function, (Provencal, G. & Taylor, R. (1983). Security for parents: Monitoring of group homes by consumers. *The Exceptional Parent*, 13, p. 39-46.

... there is an important oversight role to be played by the "candid consumer. And when encouraged, this role can lead to improved programs which parents may come to trust more fully ... Monitors do not visit homes where their relatives or wards reside ... Visits are made approximately every 2 months ... The monitor's primary responsibility is to evaluate the "feel" of each home; its appearance, atmosphere, warmth and overall sensitivity to ... the resident's well-being. Quite deliberately, monitors do not assess individual client programs, procedure compliance, or performance toward standards that are to be reviewed by other agencies.

These monitors apparently tend to identify a variety of issues that are missed at all other levels. Presently, Pennsylvania has no major commitment to this kind of monitoring.

Independent IHP Review

Under the Pennhurst court order we saw the first implementation of a peer review system for IHPs. The plans developed by the interdisciplinary teams were submitted to the Special Master for review, and the Special Master could demand changes. Later, this function was moved to the Special Management Unit. More recently, this function has either moved to the county level or it has been abandoned. It seems clear that review by a qualified professional, trained in program planning and task analysis, would help to reduce the frequency of IHPs that are completely inadequate and inappropriate (of which all of us, no doubt, have seen several examples).

IHP Based Monitoring

This activity is individually oriented. The monitor attempts to determine whether everything in the IHP is being addressed, and whether the services are appropriate and adequate. This is the original orientation taken by the Special Management Unit. The approach may be somewhat subjective, unless clear and reliable guidelines can be established to define "adequate" services, but it does seem to be an extremely useful method for assuring accountability. If performed by a separate entity, as in the SMU case, this activity serves as a backup and double-check for the case manager, who should be doing the same thing on a regular basis.

Individual Quantitative Outcome Oriented Monitoring

In this approach, instruments that are standardized and tested and reliable are collected for every individual. The data are collected by interviewing direct care and other staff, particularly the staff who know each consumer the best, plus records scrutiny. This level of Quality Assurance permits evaluation of behavioral growth, as well as of changes in program goals and service delivery patterns. Because the data are quantitative, they can be aggregated across programs or counties, in order to find pervasive patterns of excellence or of shortcomings; and the performance of providers and of counties can be compared.

This kind of system includes a "Red Flag" component, in which certain situations are defined by consensus as unacceptable. In the most extreme case, such as the detection of evidence of abuse or neglect, the system requires notification of state officials within 24 hours of the monitoring. In less extreme cases, such as failure to perform a routine audiological, notification of the state is within 30 days and the followup might be a phone call. The system includes a "Green Flag" component as well, for significant individual development, for settings in which there are no problem situations, and so forth. (This is the level at which the Temple Quality Assurance activities occur. Therefore our comments must be weighed accordingly.)

Family Surveys

Every year, every person's most significant "other" is surveyed by mail about the perceived well-being of the person. The survey can be a single sheet of paper, completed in 5 minutes, and provides an avenue

for expression of satisfaction and/or concerns. We believe the coateffectiveness of this monitoring activity is the highest of all. Each survey, even after analysis and reporting, costs only a few dollars; but the data provide one of the most sensitive indicators of overall satisfaction with the system, as well as providing one of the only avenues for officials to receive *good* news.

Moreover, the data enable the enforcement branch of Quality Assurance to look directly into situations in which a family expresses extreme dissatisfaction. Such situations should not be ignored, and it seems wise to assure that such situations reach the highest level possible, much higher, for example, than the CLA direct care staff or project director. Because it is difficult for families to negotiate the system and to reach the "higher-ups" who can do something about their concerns, the survey is a welcome innovation for families.

Individual Interviews

We believe that every person capable of verbal or signing interaction should be interviewed about their own feelings, if they so choose. These interviews, if they are treated with appropriate caution (include redundant questions and teats for acquiescence) can be treated as important and useful data. Extreme and reliable unhappiness should, for example, be treated as a Red Flag; it should call in a special review of the situation by the followup branch. (An interesting recent development is the use of consumers to interview consumers.)

Followup/Enforcement & Assistance Mechanisms

Again, these comments will outline what we perceive to be the "ideal" in the area of followup/enforcement and assistance. Such a function would ideally be situated at the state government level, for reasons stated previously, i.e., in our system, that is where the buck, and we do mean money, stops.

The ideal system would include a new division in the Office of Mental Retardation, with an employee for each unit of the state; in this case, each unit would cover no . re than 150 people in community services. The jurisdictions could be combined where they are small, and divided where they are very large (Pittsburgh and Philadelphia would require at least two followup personnel each). The physical location of the followup personnel would be decentralized, and, to the extent possible, would take advantage of existing space available to the state.

The *only* function of these people would be to receive monitoring information about the situations of consumers and act on it. The information would come from all levels of the monitoring function, but would concentrate on IHP monitoring, individual quantitative monitoring, family surveys, and individual interviews. On occasion, the followup personnel would take action on reports from parent monitors or from case managers.

The followup personnel would, in our ideal system, be accorded unprecedented powers (that is, unprecedented in Pennsylvania - what we are proposing here is actually very close to the level of power of the "broker-advocates" in the Service Integration for Deinstitutionalization

project in Virginia in the late sixties). Because of the ultimate necessity for Quality Assurance to be related to money, the followup personnel would have the authority to make a very strong recommendation to the Deputy Secretary to make adjustments - in either direction - to the base allocation of a given jurisdiction.

In the case of a remedy demanded, but none forthcoming and no reason given, the recommendation would be for a subsequent year reduction in the allocation to that county or multi-county jurisdiction. The exact amounts of these "penalties" would be placed in categories according to the severity of the "red flag." In the case of a remedy demanded, but none forthcoming, and with clear evidence that a shortage of funds is at fault, the recommendation could be for an increase of exactly the amount needed for the subsequent allocation. In the case of a remedy demanded, and provided, no action would be necessary. (When allocations are reduced, and there is a dispute about the facts of the situation, an appeal/hearing/arbitration mechanism before a designee of the Deputy Secretary would be necessary.)

In many cases, we would expect to see a problem situation for which the remedy would be a certain kind of training that is not currently available to the provider, or for which the provider (and the county) cannot pay. At the discretion of the followup personnel, funds would ideally be available in United quantities for special emergency training of this sort. The followup person could then authorize and pay for immediate assistance of the sort that is now often provided by core teams; but where the core team lacks the expertise needed, the county cannot pay, and there is no extra money in the provider's budget.

Therefore a central capability is essential, particularly for the many counties in which there is no core team and most programs have no budgeted amount for such contingencies. In most cases, we would expect the cost of these emergency training interventions to be remarkably small, but they would pay off in very high ratios for the well-being of people and programs. In some cases, it is to be hoped that central office training personnel could impart the training directly.

Because of the power this scheme assigns to the followup personnel, it seems to us that a Procedures Manual would have to be written before the first enforcer was hired. It would change rapidly, of course, but the rules and limitations of the game would have to be made clear to prevent gross misjudgments and inconsistencies. The followup personnel would have to be very skilled and experienced, but certain guidelines would be necessary to keep consistency among them: what conditions trigger an unannounced site visit, what conditions justify a warning of a base allocation reduction, and so on.

Recommendations

Following the "pie-in-the-sky" notions in the preceding section, we present here what we think may be reasonably practical directions for the immediate future. We reiterate that no such system, no matter how elegant or radically powerful, can truly do what the phrase Quality Assurance implies by itself. Vet, in the direction of improving the chances of each individual we serve to avoid and/or escape from unpleasant and inappropriate situations, we offer the following concrete suggestions.

1) Strengthen Case Management

Case management is an essential part of the Quality Assurance loop, like it or not, and it is also one of the most important. No case manager should have a caseload of over 100, when a rich body of literature suggests a practical maximum of 30. The case manager should visit every person every month (or so), and this places an upper limit on the sensible caseload. At what other level of the system can we assure that a reasonably objective third party enters the community setting and checks up on conditions? The annual review level of monitoring is completely inadequate to safeguard against abuse and neglect. Someone must visit frequently.

This, it seems to us, is an extremely urgent and appropriate direction for a significant chunk of the proposed increase in the state budget. (We realize that the number of placements is likely to become the only yardstick for success, but, in this paper, we are constrained

to ignore that and to recommend what would improve *quality*, not quantity.)

Moreover, case managers should have a standardized training curriculum that is coordinated centrally. The tower of Babel currently in existence for case management training must be ended, and the only possible locus of leadership is the state office. We also urge that this training include and emphasize value-based training, including normalization (or passing, or social role valorization). There is no reason for a case manager in this state to be ignorant of the issues raised by the ideologues.

2) Make a financial commitment to quantitative, individually oriented monitoring. (Again, this is the area of Temple's conflict of interest, so weigh our recommendations accordingly.) There is no reason, in our view, why one of the nation's leaders in community living cannot allocate less than \$250 per person per year to collect the annual individual growth data, plus the family survey data, plus the quantitative environmental scale data, that will help us demonstrate the beneficial effects of the legislature's funding. There are few stronger supports in that arena than reliable evidence that the recipients of service are growing, benefiting, and becoming progressively less dependent.

One approach in this direction *might* be to mandate that counties select or design their own systems of this kind of monitoring, but we believe that this strategy would result in far more confusion. In some areas, the state simply must take leadership, so that we can have some consistency across political boundaries.

- division at the state level, including the idea of fiscal powers. This could begin with a jurisdiction that volunteers to try out such a system, but would have to be matched with a similar jurisdiction that did not volunteer. Somehow, we must eventually move in the direction of fiscal implications for failures to act, and for successful actions. In addition, more power should be placed in the hands of those who are closer to the problems, but who are not in a situation of conflict. This would be the advantage of the followup personnel at the state level. In a fallback strategy, the followup personnel, with all the powers outlined above, could be contracted for; this would avoid the near-impossibility of hiring so many new state employees. We do not know whether this would be as effective as using state employees.
- 4) Take steps toward eventual upgrading of the licensing process, including scientific tests of reliability, and probably moving toward one or more of the nationally recognized standards— There are many avenues of "self-survey" with occasional outside verification that are available from the organizations that promulgate those standards, and these methods might replace the current minimalist licensing approach at a minor increase in cost. Moreover, it might be possible to require at least a self-survey every year, and some would argue that this kind of internal program scrutiny is educational and valuable in itself.

We emphasize, however, our own perspective: this level of Quality Assurance is largely based on assumption and inference, with no known reliability. It is *possible* to look good on such standards by cleaning up the paperwork of a facility, by promulgating a few "policies" that

have no daily impact on life in the trenches, and so forth. By itself, this could be practically a zero contribution to Quality Assurance at the level of the consumers' daily lives.

- 5) Family surveys should be mandated annually for the entire state system of community services. They can be performed by mail, and for 6000 people in community services, such an effort would cost between \$120,000 and \$240,000 total each year, including red flag notifications. This is one of the only ways in which state officials can receive good news, and it is one of the only ways in which the concerns and fears of families are expressed.
- 6) Individual interviews should be required if Recommendation # 2 is implemented, and part of the effort should use consumers to interview consumers on an experimental basis.
- 7) Parent/Sibling/Advocate monitoring should be supported in the form of one or more pilot projects. In any given county, all that is needed is enough money to support one full-time professional and an assistant, plus office and some equipment, to generate and maintain a large workforce of monitors.
- 8) Independent IHP review mechanisms should be considered as a formal requirement, because so many problems arising from careless and just plain phony written plans could be headed off by such a mechanism.

Minnesota Governor's Planning Council on Developmental Disabilities

DEVELOPMENTAL DISABILITIES PROGRAM, STATE PLANNING AGENCY

201 CAPITOL SQUARE BLDG. • 550 CEDAR STREET • ST. PAUL. MN 55101 • 612-296-4018

January 26, 1987

Celler

TO: Sue Abderholden
Anne Henry Betty
Hubbard Toni
Lippert Ed
Skarnulis
Colleen Wilson

FROM: Colleen Wieck, Ph.D.

Executive Director

REGARDING: Congressional Budget Office (CBO;

Overheads

As you may know, a leading analyst of Medicaid expenditures of ICF-MR facilities is Don Muse of the Congressional Budget Office. He has presented at several national conventions on the need for Medicaid reform. I recently received a set of his overheads that may be of interest to you. Unfortunately, I do not have a copy of his script that accompanies the overheads.

CW/amc

Enclosure

JAN : 1987

Medicaid Trends: Past, Present, and Future With Special Emphasis on ICF/MR Trends

Donald N. Muse, Ph.D. Congressional Budget Office House Annex 2, Room 431 Washington, DC 20515 202-226-2820 January 7. 1987

Medicaid Growth

<u>Year</u>	Rank	
1970	96th	
1975	61st	
1980	8th	
1985	3 Mobil Oil	
	"4" Medicaid	
	5 Ford Motor	

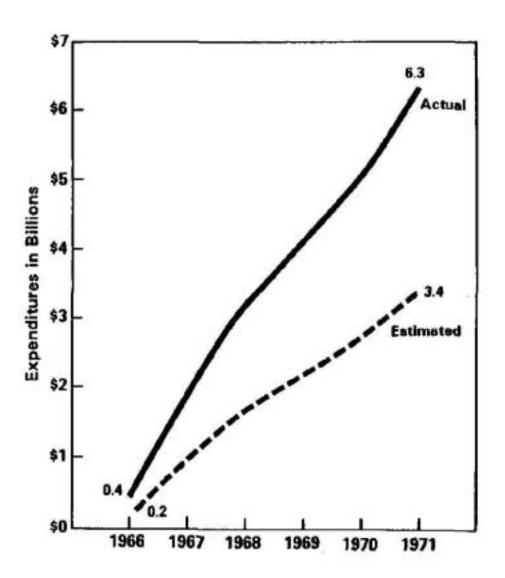
What Causes Medicaid Expenditure Growth?

Total Expenditures = f(Service Offered, Eligibility Policies, Reimbursement Practices) + Administration

or

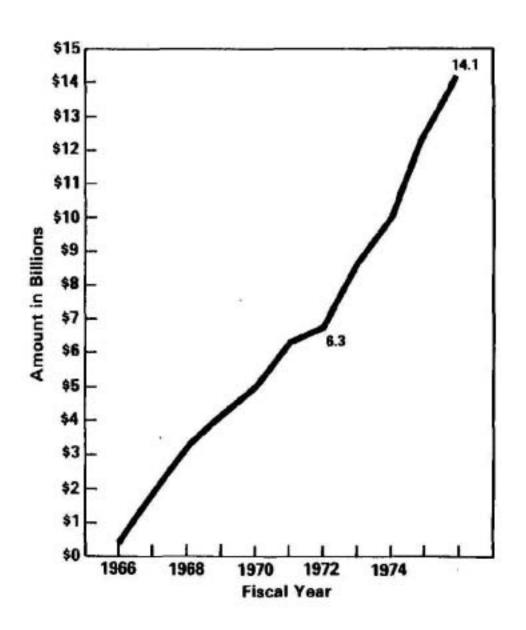
Total Expenditures = f(Utilization, Population, Price) + Administration

ERA1 Program Start-Up (1966-1971)



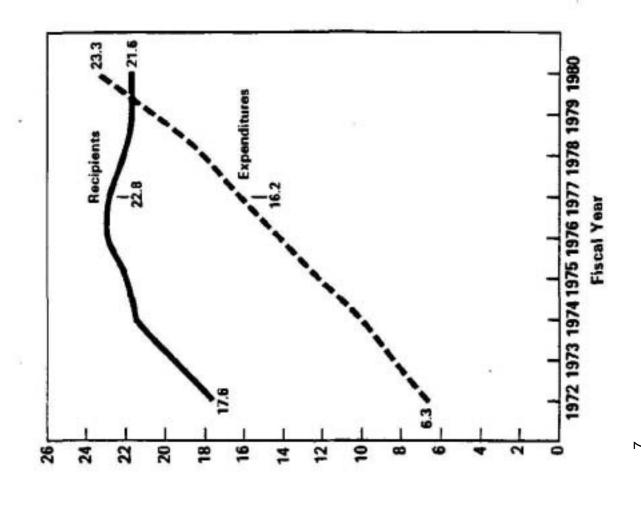
	<u>Total</u>	<u>Utilization</u>		Population	<u>Price</u>	
Era 1	31% =	11%	+	14%	+ 6%	

ERA 2 1972 Amendments (1972-1976)



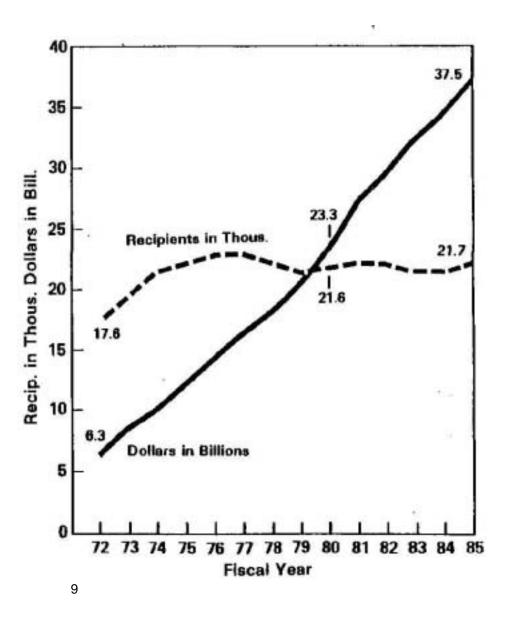
	<u>Total</u>	Utili	zation	Population		<u>Price</u>	
Era 1	31	=	11	+	14	+6	
Era 2	22	=	5	+	7	+10	

ERA 3 Medical Inflation (1977-1980)

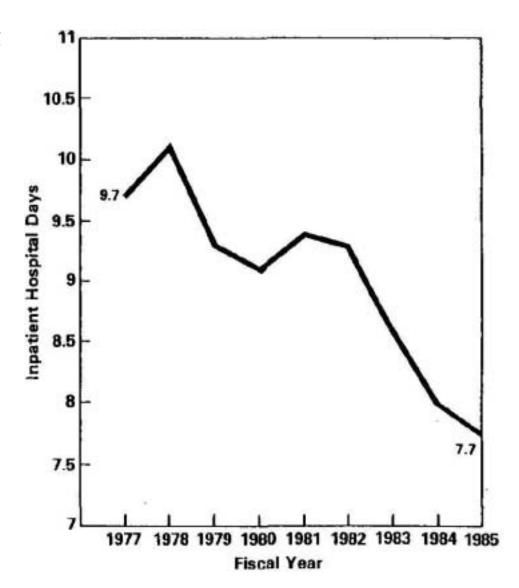


	Total		Utilization		Population		<u>Price</u>	
Era 1	31	=	11	+	14	+	6	
Era 2	22	=	5	+	7	+	10	
Era 3	15	=	1	+	2	+	12	

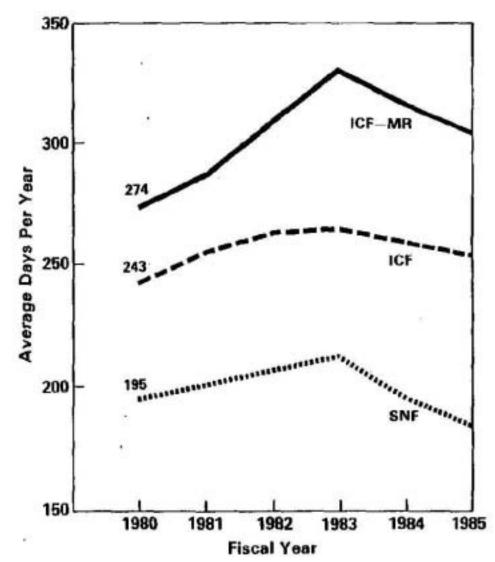
ERA 4 Fiscal Retrenchment (FY81 on)



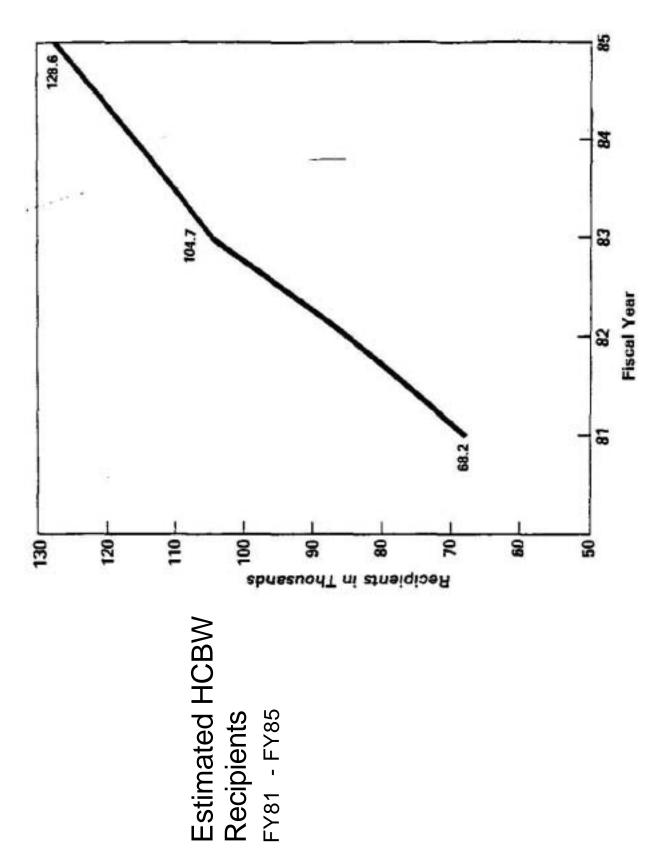
Average Hospital
Days Per Recipient
Unweighted Average



Average Days of Institutional Care by Type of Institution and Fiscal Year

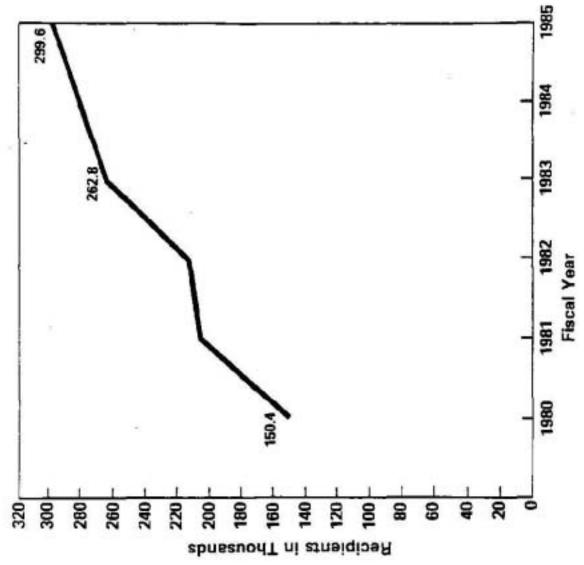








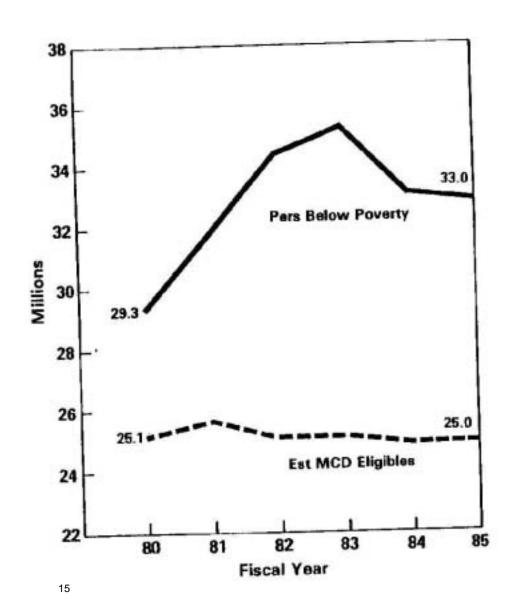
ICF Recipients with 365 or More Days of Care



Recipients of Medicaid Services by Group: FY 1981-1985

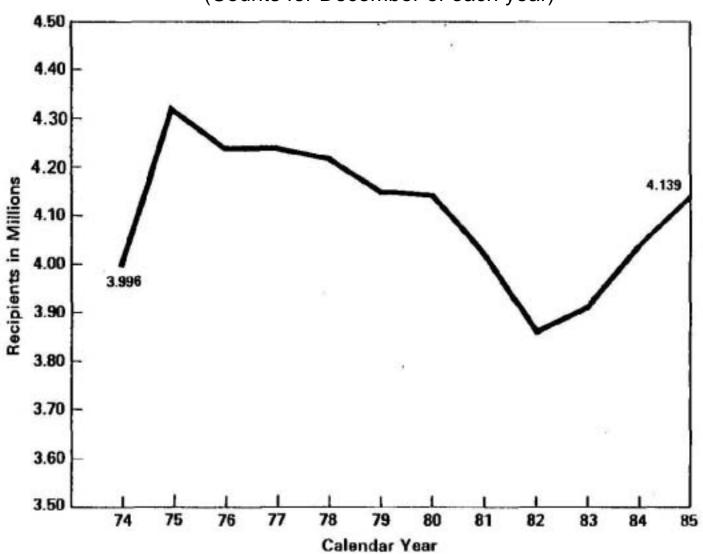
Recipient Group	Total Num of Recipie	Net Change	
	FY 1981	FY 1985	1981-85
Total	22.0	21.8	2
Cash	16.9	16.5	4
Non-Cash	1.8	2.6	+.8
Medically Needy	3.7	3.4	3
SSI Type	6.4	6.1	3
AFDC Type	14.8	15.2	+.4
Other	1.4	1.2	2

Persons Below Poverty vs. MCD Eligibles (MCD Eligibles Estimated)



Number of SSI Recipients

(Counts for December of each year)

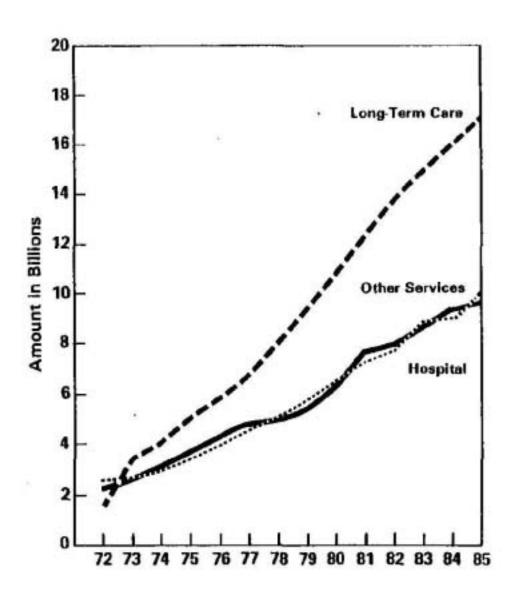


Percent Change FY 1984 to FY 1985 Selected Services

Type of Service	Increase (Decrease) in Expenditures	Increase (Decrease) in Recipients	Increase (Decrease (Decrease) Per Recipien	
ICF - All Other	11.9	3.9	7.7	
ICF - MR	10.7	3.6	7.7	
Outpatient Hospital	8.6	.3	8.3	
Inpatient Hospital	7.6	(.3)	8.0	
SNF	5.4	(2.2)	7.7	
Physicians	5.4	1.1	4.3	
Dental Services	(2.4)	(6.1)	(3.7)	

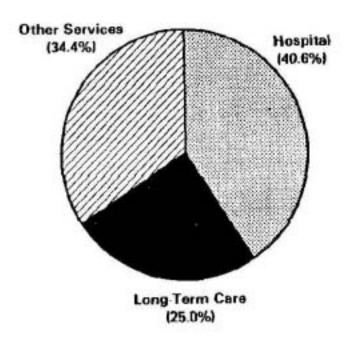
	<u>Total</u>		<u>Utilization</u>		<u>Population</u>		<u>Price</u>	
Era 1	31	=	11	+	14	+	6	
Era 2	22	=	5	+	7	+	10	
Era 3	15	=	1	+	2	+	12	
Era 4	8	=	-2	+	0	+	10	

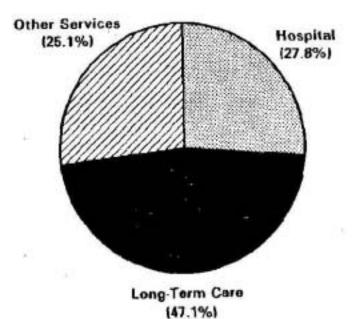
Total Medicaid Vendor Payments



Medicaid Vendor Payments FFY 1972

Medical Vendor Payments FFY 1985





The Bottom Line

 Medicaid is being driven by increases in price of services to the elderly and the disabled

Immediate Future

States

- Some program expansions
- Continued utilization reductions
- Finishing of reimbursement reforms

Prospective Reimbursement

- 81% of the dollars covered
- Perhaps 70% operational
- They lower expenditures
- How much more to be gained?

Congress

• Limited expansions

Medicaid As Seen From the Hill

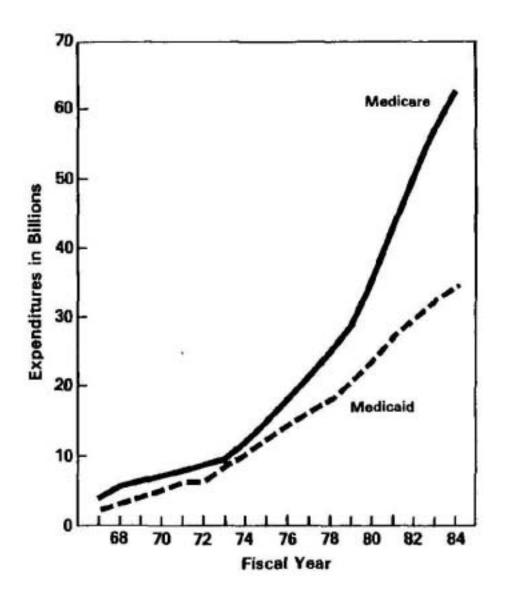
- Multiple and vocal constituencies
- A slippery program
- Its bones are showing
- "White Knights"

Administration

• ???

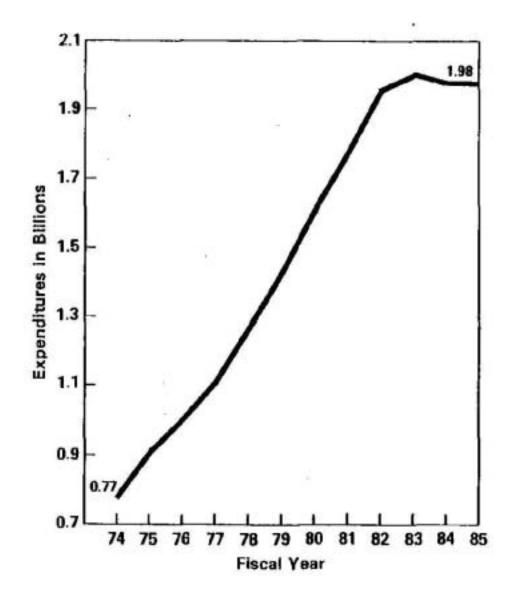
Medicare vs. Medicaid

Total Expenditures

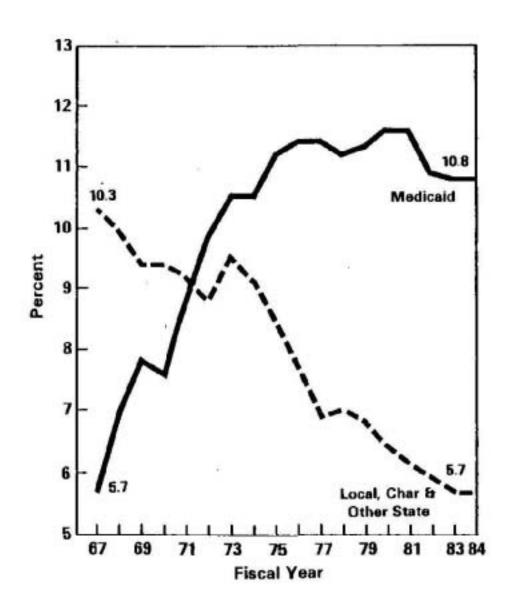


Medicaid in The Long Term

State-Only Program Expenditures FY74 - FY84



Percent of Total U.S. Health Expenditures



The Bottom Line

- Trends favor increased growth rates
- Keys to lower overall expenditure growth is what happens in LTC
- Key to federal expenditure growth is county/charity versus State struggle

Medicare Part C?

Growth in Total Medicaid Expenditures: FY 1980 to FY 1985 (In Millions of Dollars)

	F1 1000 (111 M1111	FY 1985	9. Caracath
STATE	FY 1980 Expenditures	Expenditures	% Growth 1980 to 1985
	Expenditures	Expenditures	1980 (0 1985
NORTH DAKOTA	47	117	148%
FLORIDA	392	943	141%
ALASKA	28	66	137%
OHIO	809	1767	118%
NEW MEXICO	70	148	112%
INDIANA	354	747	111%
VIRGIN ISLANDS	2	4	107%
	14	28	102%
WYOMING			
DC	168	312	86%
KENTUCKY	296	540	82%
MARYLAND	322	584	81%
MISSOURI	295	525	78%
WASHINGTON	329	584	78%
MAINE	131	232	11%
LOUISIANA	415	725	15%
OKLAHOMA	265	460	74%
COLORADO	182	316	74%
S DAKOTA	55	94	12%
CONNECTICUT	350	595	10%
PENNSYLVANIA	1058	1797	70%
MINNESOTA	590	1001	70%
WEST VIRGINIA	103	173	68%
NEW YORK	4543	7588	67%
GEORGIA	462	760	64%
NEW HAMPSHIRE	72	118	64%
NORTH CAROLINA	401	647	61%
US TOTAL	23306	37522	61%
DELAWARE	45	71	57%
AWOI	230	360	56%
RHODE ISLAND	160	250	56%
MONTANA	62	96	54%
NEBRASKA	109	167	53%
TENNESSEE	379	578	52%
ARKANSAS	235	358	52%
VIRGINIA	360	547	52%
VERMONT	59	89	52%
NEW JERSEY	756	1145	51%
CALIFORNIA	2728	4045	48%
IDAHO	52	76	47%
NEVADA	45	66	46%
TEXAS	981	1414	44%
PUERTO RICO	97	139	43%
ALABAMA	263	375	43%
MASSACHUSETTS	1009	1433	42%
MICHIGAN	1071	1517	42%
UTAH	79	110	39%
ILLINOIS	1192	1653	39%
WISCONSIN	687	942	37%
OREGON	179	239	33%
		256	30%
KANSAS	197	250	300
	197 211	274	30%
KANSAS MISSISSIPPI HAWAII			

Minnesota Governor's Planning Council on Developmental Disabilities

DEVELOPMENTAL DISABILITIES PROGRAM, STATE PLANNING AGENCY 201 CAPITOL SQUARE BLDG. • 550 CEDAR STREET • ST. PAUL. MN 55101 • 612-296-4018

March 11, 1987

Colleen

TO: Minnesota MR Reform Team

Members, Public Policy Committee, Governor's Planning Council on Developmental Disabilities

FROM: Colleen Wieck, Ph.D.

Executive Director

REGARDING: Final Letter on MA Reform

After some minor revisions, we delivered this letter to Helen Darling on February 20, 1987. Helen will send us a copy of the Chafee bill for our review and comment.

CW/amc

Attachment

Minnesota Governor's Planning Council on Developmental Disabilities

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February 13, 1987

Ms. Helen Darling
Ms. Mary Brecht
c/o Senator Dave Durenberger
353 Russell Senate Building
Washington, DC 20510

Dear Helen and Mary:

In follow-up to our meeting in Minneapolis on Medicaid Reform for people with developmental disabilities, the Minnesota work group has met and would like to offer several ideas for your consideration.

We believe that Minnesota is proceeding in the right direction by moving individuals with developmental disabilities from our regional centers (state hospitals) to community settings. Continued depopulation of state-operated facilities is our primary concern and should be accelerated through federal incentives. We are willing to allow community agencies serving more than 15 residents to continue as is without any federal changes in their funding since we have so many agencies in Minnesota already undergoing voluntary downsizing.

In drafting legislation, we believe that Senator Durenberger could endorse:

- 1. Using the state Medicaid Plan as the vehicle for reform. It would be up to every state to propose how to make changes.
- 2. Building in fiscal incentives to match policy through one of three different mechanisms or combinations of these approaches:
 - a. Freeze the federal share of Medicaid used for state-operated regional centers (state hospitals).
 - b. Decrease the federal match by 2.5% annually for any state-operated regional center (state hospitals).

Ms. Helen Darling Ms. Mary Brecht Page 2 February 13, 1987

- c. Provide an increased federal match (2.5% annually) for nonfacility-based community programs and supports (family support and respite care).
- 3. Directly address the issues of employees, economic impact, and buildings as state institutions face closure:
 - Buildings: During the comprehensive study of Minnesota's state hospitals, we were contacted by federal officials regarding converting vacant buildings into federal prisons; we were approached by a private organization that wanted to purchase Anoka Regional Center, and we were informed by Pennsylvania officials about converting institutions into data centers (record storage sites) or regional service integration centers. There are developers interested in our state institutions, particularly, property on lakes. We also have state agencies interested in using the campuses for prisons or veteran's homes. Senator Boschwitz has discussed enterprise zones for economically depressed areas. A similar concept can be adapted for vacant regional centers.
 - b. Economic Impact: Whenever the issue of economic impact is discussed, the topic focuses on the loss of money to one county where the regional center is located. Based on the 1984 comprehensive study of regional centers, we have learned the following:
 - Local officials want to multiply the total budget by a multiplier of 10 and claim the economic impact on the local town is that product. Based on our work, the economic impact multiplier is closer to 2.
 - Economic impact is a function of where employees live, not where

Ms. Helen Darling Ms. Mary Brecht Page 3 February 13, 1987

the regional center is located. The greater the dispersion of the employees, the less economic impact on the immediate location of the regional center.

Funds will continue to be spent where people with developmental disabilities live. Economic impact shifts with the location of the residents. While there are 8 counties that have economic gain because of the location of the regional centers, there are 79 counties that could improve their economic condition by bringing residents home.

We are enclosing a draft set of principles that our national counterparts have agreed should guide Medicaid Reform. We look forward to continued discussions with you.

Colleen Wieck, Ph.D. Executive Director

CW/amc

Enclosure

Cordially,

Minnesota Governor's Planning Council on Developmental Disabilities

DEVELOPMENTAL DISABILITIES PROGRAM. STATE PLANNING AGENCY 201 CAPITOL SQUARE BLDG. • 550 CEDAR STREET • ST. PAUL. MN 55101 • 612-296-4018

April 27, 1937

TO: Interested Persons

FROM: Colleen Wieck, Ph.D. Executive Director

REGARDING: Medicaid Demonstration Projects

I recently reviewed the attached article on Medicaid Demonstration Projects published in Health Care Financing Review. As you know, Minnesota is one participating program and is mentioned in this article. I have summarized the major findings of the article:

- Implementation: All programs have consistently taken longer to implement than expected.
- Enrollment: Various difficulties and delays are mentioned.
- 3. Provider Participation: All demonstrations appear to have benefitted from the emerging competitive environment among providers caused by low hospital occupancy, surplus of physicians, and growth in HMOs.
- Rate Setting: Some observers assert that rate setting will be the single most important issue in determining program viability.
- 5. Management Information Systems: The severe MIS problems of the first year are being solved.
- Quality Assurance: Tends to be utilization re view in order to reduce unnecessary care.
- Management Concerns: Extremely challenging projects because of staff turnover and consult ant performance problems.

Special Report

Status of the Medicaid competition demonstrations

by Robert E. Hurley

In 1982, the Health Care Financing Administration approved funding for demonstration programs in six States to test a variety of alternative delivery strategies for Medicaid recipients. A number of innovative health service delivery features have been used in these programs, including competition, capitation, case management, and limitations on provider choice. These strategies have been tried in order to address the key Medicaid problems of cost containment and access to appropriate and high qualify care. This article provides an overview of how the demonstration sites have approached the task of designing, developing, and implementing their various programs.

Introduction

In 1982, the Health Care Financing Administration (HCFA) approved funding for demonstration programs in sis States. The programs were to test a variety of alternative delivery strategies for Medicaid recipients. To address the key Medicaid problems of cost containment and access to appropriate and high quality care, the programs have used a number of innovative health service delivery features including competition, capitation, case management, and limitations on provider choice. The programs have incorporated these features into several different types of organizational arrangements in order to test a number of assumptions about how the delivery system can be effectively changed.

In the fall of 1983, HCFA awarded a contract to a consortium of researchers under prime contract with the Research Triangle Institute¹. The researchers were to conduct a 4-year evaluation of these demonstration programs. This evaluation is designed to perform a comprehensive assessment of the demonstration strategies including implementation and operational issues as well as program outcomes. The evaluation plan includes both quantitative and qualitative components to accomplish this goal.

The analysis of program effects, based on such outcomes as cost, use, access, quality, satisfaction and

The consortium also includes the University of North Carolina-Chapel Hill. Medical College of Virginia of Virginia Commonwealth University, Lewin and Associates, American Enterprise Institute (or Public Policy Research, New Directions for Policy, and Tillinghast, Nelson & Warren.

This report was funded by the Health Care Financing Administration (Grant No. 500-83-0056). The opinions expressed are those of the author and should not be construed as representing the policy of HCFA

Reprint requests: Robert E. Hurley, School of Public Health, 253 Rosenau Hall, Chapel Hill, North Carolina 27514.

provider participation will be conducted with primary and secondary data collected during operation of the programs. The evaluation team is also examining design, development, and implementation issues. This is primarily being done through a series of detailed, multiyear case studies carried out at each of the demonstration sites by personnel from Lewin and Associates, the American Enterprise Institute, and New Directions for Policy. This article describes the set of case studies performed in the sites during 1985-86. The final report of the evaluation is due in 1987.

Purpose of the demonstrations

The demonstration programs are exploring whether alternative approaches to providing care can respond to the many problems that have plagued the Medicaid program during its 20 years of existence. These problems include, but arc not limited to, the following:

- Excessive rates of cost increases.
- Unnecessarily high rates of use for selected services.
- Inappropriate patterns of use such as reliance on the emergency room for nonemergency care; high rates of self-referrals to specialists; and "doctor shopping," i.e., capricious changes in medical providers.
- Lack of access to providers offering continuity of care.
- Concern that available providers may not provide high quality care.
- Declining physician participation for such reasons as unreasonably low fees, delays in receiving payment on a timely basis, and administrative burdens in negotiating the payment system.

Many of these problems are interrelated and self-reinforcing, suggesting major structural reform must be explored in the Medicaid program. These demonstrations with critical elements of competition, capitation, and case management are among several delivery system reforms currently being evaluated by HCFA.

Competition has been included in these programs in order to attempt to bring providers into Medicaid who have traditionally had little or no involvement with the program. By expanding provider participation, problems of access can be addressed and, ultimately, costs may be contained and reduced by increased competition among new and existing providers. In response to the entry of new providers, traditional Medicaid providers are expected to modify their approaches to serving the Medicaid population in order to avoid loss of patients.

Financial risk-sharing with providers, in the form of prepaid capitated rates, is also being explored extensively in the demonstrations. The setting and payment of rates in advance to cover specified services gives participating providers concrete performance targets that they must meet to remain viable. By establishing rates below existing equivalent fee-for-service payment amounts, the demonstration programs can be assured of cost savings. Correspondingly, prepayment gives providers increased revenue predictability and improved cash flows. More significantly, providers come to recognize that substantial financial savings might be achieved by judiciously managing enrollee utilization, including limiting unnecessary use and substituting less costly services.

Case management attempts to address cost, use, and access problems by taking advantage of the pivotal role of the primary care provider as the point of access to the health care system. By linking and locking-in an eligible person to a primary care case manager, who can both provide and manage a substantial portion of a recipient's medical care, patterns of service use may be changed and access to appropriate care assured. The relationship of the provider to the Medicaid program and to the recipient can be structured in a number of ways, using contractual arrangements and risk-sharing approaches, which are designed to foster effective case management and to achieve program goals. The demonstrations represent a broad spectrum of planned variations intended to do this.

Background

An understanding of the development of the programs requires some background on the individual demonstrations. In Table 1, a synopsis of selected program characteristics is presented. The following is a brief description of each program.

Monterey—Operated by the Monterey County (California) Health Initiative, until its termination because of insolvency in March 1985, this demonstration provided a mandatory primary care case manager program. The primary care providers were paid on a fee-for-service basis with a case management fee; providers were not at financial risk for specialty and hospital care. Participating providers included physicians, health centers, and hospital outpatient departments. Enrollment reached 26,000 in December 1994, with 160 participating case managers.

Santa Barbara—This demonstration, operated by the Santa Barbara County (California) Health Initiative, under a prepayment contract with the State Medi-Cal agency, is a mandatory primary care case management program. The initiative contracts on a prepayment basis with such primary care providers as individual physicians, physician groups, and health centers; these groups are then responsible for providing primary care services and for authorizing specialty and hospital care. The program is fully operational, with approximately 21,000 enrollees and 12S participating case managers.

Florida—The State Medicaid agency originally planned four separate modules to develop alternative delivery systems using elements of prepayment.

competition, and case management. Three of the four modules are no longer part of the demonstrations; they have either been terminated or undertaken by the State as nondemonstration programs. Planning for the fourth module continues and involves the development of a prepaid case-management program for the frail elderly. This program is expected to be implemented in 1986 in the Miami area; its objective will be to avoid nursing home placement by the provision and coordination of medical and social services.

Minnesota—The State Medicaid agency is conducting demonstrations in three counties; Dakota, Itasca, and Hennepin (Minneapolis). In Hennepin and Dakota (a suburban Minneapolis county), seven health organizations have entered into prepayment contracts to enroll eligible individuals who may select from any of the plans. In Itasca, a small rural county, the county receives a prepayment for each enrollee, and providers are paid on a fee-for-service basis with surpluses and deficits shared by the county and the providers. Enrollment is mandatory in the counties with the exception of Hennepin, where only 35 percent of the population will be randomly assigned to enrollment, and the remainder will stay in the traditional Medicaid program. Total enrollment as of July 1986 was approximately 11,700.

Missouri—The State Medicaid agency operates a mandatory enrollment program for Aid to Families with Dependent Children (AFDC) recipients of Jackson County including Kansas City. Most of the eligible population is enrolled with five prepaid health service organizations: two hospitals, two neighborhood health centers, and an individual practice association (IPA); these organization; are responsible for providing, or authorizing virtually all medical care. Approximately 20 percent of the eligible group are enrolled in the physician sponsor program (PSP) in which 55 primary care physicians are paid on a fee-for-service basis and receive a case management fee to manage care, including authorizing referral and inpatient services. Total enrollment is approximately 23,000.

New Jersey—This demonstration provides for the voluntary enrollment of Medicaid eligible individuals with primary care case managers, physicians and health centers, which are paid on a prepayment basis for each enrollee. The prepayment is structured to compensate the case manager for primary care services directly provided and to place the case manager at some financial risk for referral services. Operated by the State Medicaid agency, the program has been implemented in several counties and statewide implementation is planned. Enrollment in early 1986 was approximately 9,500.

New York—This mandatory program in Monroe County including Rochester, is managed by a county agency under a prepayment contract to the State Medicaid agency. This county agency, MediCap, contracts with a network model health maintenance organization (HMO) to provide case-managed services to the enrolled population. The provider members of

Table 1 Selected demonstration characteristics, by demonstration site

Demonstration site	Date of implementation	Type of enrollment	Organizational structure	Eligible population	Participating providers	Provider payment
Celifornie Monterey County'	June 1963	Mandstory enrollment:	Risk-assuming intermediaries	Categorically eligible and	Case managers are primary care	Intermediary
Santa Barbara County	September 1983	provider	which contract with primary care organizations and individuals	medically needy	providers, including physicians, clinics, and hospitals	Monterey— tee for-service plus fee-Santa Barbara- capitation
Florida ³	Planned	Voluntary enrollment	State contracts with prepaid plan	Supplemental Security Income—trail elderly	Hospital	Capitation
Minnesota	2010/02/03/03	11220020000	200000000000000000000000000000000000000		22:00:00:0	12007/40302
Dakota County	December 1985	Mandatory enrollment;3	State contracts with prepaid	Aid to Families with Dependent	Primary care organizations	Capitation for plans in
Hannepin County	December 1985	choice of provider	health plans or county (Itasca)	Children, Aged, Blind, Disabled	or game attoria	Hennepin and Dakota and for
Rasca County	August 1985	-11-01-0000 10000	0.0 0.0 0.0 0.0 0.0 0.0 0.0 0.0 0.0 0.0			county in Itasca
Missouri			- Company			
Jackson County	November 1983	Mendatory enrollment; choics of provider	State contracts with prepaid health plans and individual physicians	Aid to Families with Dependent Children	Plons include hospitals, inclvidual practice association, neighborhood health centers, and individual physicians	Capitation for prepaid health plans; fee-for- service with fee for physicians
New Jersey	June 1983	Voluntary enrollment	State contracts with primary care organizations and individual physicians	Categorically eligible	Case manager must be primary care provider including health centers and physiciana	Capitation
New York						
Monroe County	June 1985	Mandatory enrollment, choice of provider	Intermediary which contracts with prepaid health plans	Aid to Families with Dependent Children, home rollef, medically needy	Prepaid health plans	Capitation

Terminated March 1986

²Three of four proposed modules lerminated August 1984.

Random assignment employed in Hermepin County.

the network include physician groups, neighborhood health centers, and hospitals; these members receive prepaid amounts to cover a broad range of medical services, which are either provided or arranged. MediCap is attempting to recruit other prepayment plans; enrollment had reached approximately 25,000 in February 1986.

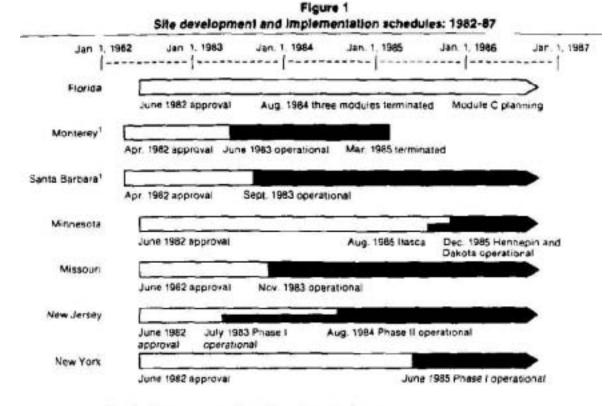
Key terms

The variations in program design permitted and encouraged in the demonstrations make it important to clarify several terms used to describe certain program aspects across the demonstrations. Among the key terms and their definitions are the following:

Risk assuming intermediary— In two States, California and New York, intermediary organizations have contracted with the State Medicaid agency to manage the program in return for a fixed prepaid amount received for each eligible person enrolled in the program. These intermediaries, which provide no medical services themselves, are responsible for arranging service provision with area medical providers.

Prepaid health plans or organizations—These provider organizations enter into agreements to provide services directly with the State Medicaid agency or the risk-assuming intermediary organization. These organizations may range from conventional prepaid organizations, like HMO's, to other providers, such as hospitals and health centers; typically, these organizations are paid on a prepayment basis for a specified range of services.

Primary care case managers—Several of the programs have primary care case manager (PCCM's). In these programs, primary care physicians are formally designated as the case manager, i.e., gatekeeper, for a group of enrollees. PCCM's may have contractual relationships with the Medicaid agency, intermediaries, or prepaid health plans.



Planning already under way at time of demonstration funding approval

PCCM's may be compensated by a prepaid payment for specified services or on a fee-for-service basis. In fee-for-service situations, the PCCM is usually paid a supplemental fee to perform case management duties. Some of the participating prepaid plans have elected to use the case management approach, and others have not.

Capitation—Programs have established prospective rates of prepayment, based on the average historical cost, to provide a specified set of services to eligible individuals. These rates, called capitation payments, represent the principal means of structuring risk sharing among the various organizations participating in each demonstration. The capitation rate may be set to include ail Medicaid services, or the rates may be limited to a subset of services such as primary care services.

Status of selected issues

A number of critical demonstration program issues may be examined across the sites. These issues include: implementation, rate setting, enrollment, management information systems, provider participation, quality assurance, provider payment and risk-sharing, and administration and management.

Implementation

As shown graphically in Figure 1, the periods of time devoted to implementation have varied among the programs, but programs have consistently taken longer to implement than expected. These delays are particularly troublesome in time-limited demonstration programs. Program administrators report the tensions between getting started prematurely, on the one hand, and jeopardizing program credibility (support) and viability (funds) by being too deliberate, on the other hand. Attempting to satisfy conflicting interests of (he Federal funding agency and the provider community puts severe countervailing pressures on those responsible for the programs.

The implementation period has been marked by enormously time-consuming efforts at consensus building and tradeoff negotiations with providers. Most important, these negotiations can result in program design changes that can fundamentally affect or alter the programs goals. For example, critics of Monterey have suggested that in the face of provider opposition, Monterey negotiated fee-for-servicepayment rates that were higher than conventional Medi-Cal rates; later efforts to tighten controls were strongly resisted. New Jersey granted a 1-year waiver of risk to early enrolling providers to break an impasse and begin operations. In New York, inability of provider groups to form risk-sharing entities limited competitive efforts to existing area HMO's. Missouri expanded its program, which initially was to

encompass only prepaid plans, to include an entire set of Medicaid physicians who participate in the PSP. This expansion was necessary to defuse the providers' opposition without relinquishing program aims. As discussed earlier, the trade-off between getting started with existing Medicaid providers or attracting new providers has been another implementation dilemma faced by the demonstrations in a number of sites.

Interorganizational end intergovernmental relationships have also played a not-unexpected role in these public programs. Federal, State, and local officials have had varying expectations and commitments both to the overall program and selected program features. These concerns have surfaced in the design and the implementation phases. In some cases, disputes have arisen in purely technical areas like rate setting; in others, the concerns have followed more traditional jurisidictional disputes, including where the locus of authority should reside to make changes necessary to implement the program. In several cases, municipalities operating health service facilities have been reluctant to embrace the programs because of fear of incurring undue risk. This fear is a consequence of municipalities' perceived uncompetitive positions and the vulnerable position in which their indigent care responsibilities may place them.

Enrollment

The enrollment process actually includes a number of related procedures:

- Consumer information and education.
- Provider selection (or program and provider selection in New Jersey).
- Notification of case manager of enrollment/disenrollment.
- · Disenrollment and provider changes.
- Grievances.

Consumer information and education—The public assistance eligibility system and its data files play a critical role in identification of and communication with consumers in all sites, Most programs have personnel assigned to local welfare offices; these personnel describe the program and selection options available to eligible individuals, including using written and audio-visual materials. Only New Jersey has permitted this function to be carried out by provider-based personnel. Other sites permit some dissemination of provider-developed and programapproved promotional materials to aid in enrollee recruitment. Although this education includes an orientation to key features of the demonstration, most programs and providers consider this to be only the beginning of the learning process. This process is meant to give enrollees an understanding of the implications of limited choice and managed care.

Provider selection—All of the demonstration programs are mandatory for targeted eligible groups, with the exception of New Jersey, which has a voluntary enrollment program. Each demonstration does permit and, in fact, requires selection of the

participating plan or provider from whom the individual will receive services. Despite this selection opportunity, a high percentage of individuals fail to exercise it. Surveys in Monroe County, for example, suggest that only about two in three recipients make their selection themselves. When no selection is made, various forms of automatic assignment are used. This can produce other problems: In Missouri, it has been surmised that auto-assigned enrollees have higher out-of-plan use rates than self-assigned enrollees; in New York high rates of provider switching among auto-assigned enrollees have led some providers to develop their own schemes of transferring capitation payments in order to reconcile accounts.

Provider notification—Once selection of a provider is completed, this information must be communicated on a timely basis to the responsible plan or provider. Delays in this process, which were common, if not pervasive, in the first year of operation, arc problematic for the program, confusing for patients, and costly for providers. Reviews conducted in Monterey after termination noted that as much as \$1.5 million dollars in services may have been provided to individuals not appropriately enrolled with the Initiative; thus, the Initiative was not eligible to receive capitation payments from the State for them. The difficulties initially noted in this area have been solved in most sites, although exceptions continue to occur, especially for the more recently implemented programs.

Disenrollment and provider changes—The guarantee of 6-month eligibility in the demonstrations has greatly simplified the disenrollment problem, though disruptions still occur at the end of the guaranteed eligibility period. Another area of considerable concern has been the disruption of patient-provider relationships for individuals whose on-going providers are unwilling or unqualified to become case managers. This concern has been most commonly noted in Santa Barbara, but has arisen elsewhere, especially for the chronically ill and disabled (often supplemental security income-eligible) who have had long-standing provider relationships. This issue has resulted in some program critics and supporters questioning whether case management is appropriate for this class of individuals. In New York, for example, these people are given the opportunity to opt out of the demonstration.

Grievances—All programs provide grievance systems for enrollees to register formally concerns, problems, and complaints about any aspect of the program. The number of grievances have been relatively limited considering the potentially disruptive nature of the demonstrations and the relative generosity of the traditional Medicaid programs in which recipients were previously enrolled. Although most sites are systematically reviewing the nature of grievances to assess overall trends, findings have not been notable. It does appear that as the availability of personnel to handle grievances increase the number of grievances being filed also increases.

Provider participation

The critical issue of provider participation can be explored by looking at three general dimensions; the provider environment, recruitment, and attitudes of participating providers.

Provider environment—In view of the historically low rates of physician participation in Medicaid and the dissatisfaction expressed by many of those who do participate, it was difficult to anticipate how the provider community would respond to these demonstration programs. Characteristically, responses have varied across the demonstration sites, suggesting the importance of local medical service market conditions. The status of the State Medicaid programs, including fiscal crises with anticipated or actual program and payment reductions, has also been widely recognized as having fostered a climate for change, i.e., program reform.

The flexibility of the demonstration programs to involve provider types, which traditionally have not participated in Medicaid, has expanded the options available. However, it has been common for some commercial prepayment plans, like HMO's, to express hesitancy about serving the Medicaid eligible for the first time. For other providers, such as neighborhood health centers, the opportunity to gain experience with prepayment has been welcomed, though with some apprehension. This apprehension is attributed to providers' limited financial reserves to absorb adverse consequences and their lack of knowledge about managing risk. For still other large institutional, often teaching, providers with major commitments to care for the indigent and Medicaid populations, participation was inevitable even if they chose to participate "passively," i.e., by making few administrative, staffing, and procedural changes in response to program incentives.

Virtually all the demonstrations appear to have benefited from the emerging competitive environment among providers. Characteristics of this environment include: hospital occupancies at unprecedented low levels, a growing surplus of physicians, and growth in group practices, health maintenance organizations (HMO's), and preferred provider organizations (PPO's). Given this environment, providers have shown interest in participation based on the following reasons:

- Opportunity to solidify or expand market share.
- Potential to earn higher incomes from Medicaid patients under the demonstrations than fee-forservice, unmanaged care (by improved control over enrollee utilization).
- Chance to gain the benefits of more timely and predictable cash flow from prepayment.
- Fulfill an expected role for public institutions with large Medicaid constituencies such as municipal hospitals.

This competitive climate is likely to continue for the duration of the demonstrations and beyond.

Provider recruitment—During the development of demonstration programs, most programs, initially,

expressed their intent to try to bring into the demonstrations providers who had not previously been major participants with the Medicaid program. These programs were trying to integrate the Medicaid population with mainstream providers and to assure that participating providers could give the desired quality and continuity of care. Some demonstration programs report progress in this direction, although they are more likely to attract traditional Medicaid providers, such as public hospitals and health centers. The recruitment of conventional prepayment organizations has been hampered by a number of factors. Program design features and capitation payment arrangements have effectively excluded HMO's in New Jersey; low rates have discouraged participation in Florida; and general uncertainty about the viability of serving the intermittently eligible Medicaid population has surfaced in a number of programs. As a result of these factors, HMO participation has occurred only in Minnesota (five HMO's, Missouri (a single independent practice association), and New York (a single network-model HMO).

Competition among providers to enroll eligibles has been limited, somewhat at variance with the avowed aim of these competition demonstrations. The reasons for this appear to be related to the following kinds of concerns among providers:

- Is prepayment appropriate for the Medicaid population?
- Do the State or other public agencies have the wherewithal to design, implement, and manage effectively such complex programs?
- Are case-management responsibilities compatible with the primary care provider's other functions and duties?
- Are risk sharing and opportunities for gain appropriately balanced i.e., are rates and methods of payment fair and adequate?

Until these questions are answered so as to allay provider concerns, provider recruitment and, thus, program implementation are delayed. Providers' full potential to compete for more Medicaid recipients can only be realized after these problems are substantially resolved.

It is for this reason that fostering provider competition has emerged as a secondary goal to getting programs implemented. *In* order to allow the program to gain momentum and credibility, a number of demonstration programs have chosen to negotiate intensively with only a few providers rather than awaiting broader provider participation. The benefits of a spectrum of providers arc apparent in the more mature programs, which have enabled providers to learn, initially, that the program is viable; then providers are able to examine their experience to determine if expansion in enrollment is appropriate for them. For example, in Missouri, some providers are now beginning to plan marketing initiatives to expand their enrollments by attracting recipients from their competitors assuming, as discussed earlier, capitation rates remain acceptable.

Participating provider attitudes—The first year studies described how many providers initially reacted to their program responsibilities. To a certain extent, the near universal difficulties with management information systems (MIS's), including the absence of such key program elements as prior authorization procedures, dominated their experiences and attitudes. The second year has seen much improvement in this area and provider attitudes seem to have improved accordingly.

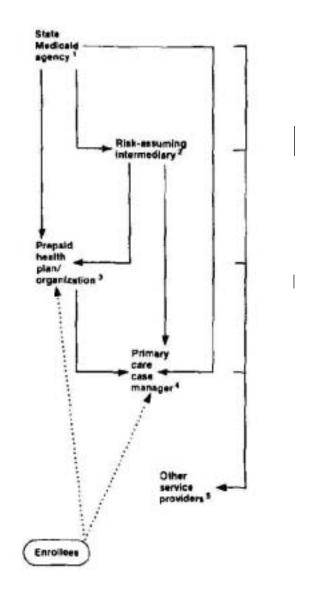
Some of this adjustment must be acknowledged as acclimatization to prepayment for those providers with little or no previous experience with it. This has meant the development of budgeting and other financial systems as well as, in some cases, case management procedures. In addition, making the gatekeeper role an explicit responsibility, in those plans using it, has likewise proven challenging and created a whole new range of issues in inter-provider relationships between primary care physicians, specialists and providers of institutional care. For the hospitals that have chosen to participate as prepaid health plans, varying responses have been noted: Some, like the Monroe County area hospitals, have developed extensive in-house case management systems, and others, as in Missouri, have largely continued providing services as usual. A particularly sensitive issue to be addressed when program outcomes are analysed, will be whether such providers should be permitted to continue as participating plans if greater cost savings can be achieved without them.

Providers report that they need time to understand and appreciate the subtleties and complexities of case management. Enrollees need learning time as well, especially concerning the lock-in (limitation on choice) aspects of the program. Coordinating the delivery of services takes efforts providers may not have been previously expending and requires development of formal, continuous 24-hour coverage, as well as referral and treatment authorization systems that lake time to establish. Programs also have to devise strategies to curb out-of-plan use, including deciding whether to pay other providers for unauthorized care. Interestingly, one of the most irritating aspects of the transition has been the requirement that pseudo (dummy) claims be submitted for prepaid care to enable the demonstrations to be evaluated. For some prepayment organizations such as in Minnesota. preparation of these types of claims is a new responsibility for which additional staff are required. However, most providers report high levels of satisfaction with the efforts of State and Initiative personnel to accommodate their concerns and respond to their problems.

Provider payment and risk sharing

Among the most difficult and critical features in designing the demonstrations has been the complex configurations in the multitiered risk-sharing arrangements developed across the programs. These arrangements, in effect, manifest the assumptions

Figure 2 Structural relationships of tiers in the demonstration programs



1State Medicaid agency may contract with risk-assuming intermediary prepaid health plans or organizations primary care case managers.

2 Risk-assuming intermediary may contract with prepaid health plans or organizations, primary care case managers

3Prepaid health plan or organization: may enroll individuals without assignment to specific case manager, may use individual case manager approach with employed or contracted physicians 4Primary care case manager may enroll individuals directly, may be engages by prepaid plan or organizations to perform case management

5Other service providers participation and payment arrangements may be set or negotiated By various tiers in different sites

about the kinds of incentives needed to make the demonstrations successful. To illustrate this it is useful to enumerate the levels or tiers around which their payment systems are organized. The tiers include the following:

- State Medicaid agency.
- Risk-assuming intermediary (where applicable).
- Prepaid health plan or organization (where applicable).
- Primary care case manager (where applicable).
- Other providers.

In Figure 2, an overview of these tiers is provided across the demonstrations, illustrating how risk and responsibilities are distributed across the tiers.

The State Medicaid agency either directly contracts with providers or engages a risk-assuming intermediary as in the California and New York programs. In these programs, the State delegates the administration of the program to such an intermediary and the State also sets a capitation rate to enable it to acquire covered services for enrollees. This is customarily a discounted rate (usually 95 percent), based on the historical fee-for-service equivalent payment. The principal advantage of this system is that the Slate can guarantee itself savings, and the intermediary has an incentive to acquire services for enrollees at the lowest available cost.

The next tier, the prepaid health plan or organization, may be engaged by the State directly Or by the intermediary to assume responsibility for providing covered services. In the State-administered programs, such as Missouri and Minnesota, these plans are capitated to place the prepaid health plan or organization at financial risk. Missouri does permit an exception to this, as noted earlier, with the physician sponsor program, which is not capitated but is paid fee-for-service with a case-management fee. In New York, where MediCap is a capitated risk-assuming intermediary, the prepaid health plan is a network-model HMO and is also capitated, functioning like a secondary intermediary.

Significant variation among the programs is found at the level of the PCCM. In some demonstration programs, case management is an explicit component. In others, case management is not a uniform feature, though prepaid plans may elect to use it as a cost and utilization control technique. In Santa Barbara, the intermediary requires participating providers to be case managers and pays the PCCM's on a capitated basis for primary care services; in Monterey, the method of payment was fee-for-service with a casemanagement fee, similar to the Missouri Physician Sponsors Plan. In Itasca (MN), the county is capitated and the PCCM'S are paid fee-for-service with both the county and the PCCM's sharing in surpluses or deficits. In the other Missouri provider arrangements and in Hennepin and Dakota programs, the prepaid plans IPA's, HMO's, neighborhood health centers, and hospitals, may elect one of the

- Not to have individually responsible case managers.
- To contract with and capitate PCCM's.

• To employ a PCCM physician and pay a salary.

In New York and New Jersey participating providers are expected to adopt the case-management approach. These variations in commitment to and employment of the case-management concept typify differing assumptions about its expected usefulness in containing costs and improving access.

The final tier relates to risk sharing for nonprimary care providers, including inpatient care, medical specialists, or nonphysician providers. The demonstrations are experimenting with a number of arrangements, ranging from separating this entirely from the primary care payment systems to putting the prepaid plan or PCCM at full risk for all care. It is at this tier that the treatment and referral authorization systems become highly important; the systems are closely linked with how financial risk for nonprimary care services is apportioned among the various tiers.

At all of these tiers variations can be found reflecting the exploratory and adaptive nature of the risk-sharing process. The variations may be attributed to the assumptions of program developers about the effectiveness of various risk-sharing-arrangements. Further, the variations suggest that some programs attempt to be highly explicit about how participating organizations and individuals are to achieve cost savings; others leave these decisions to the managerial discretion of the plans and providers.

Rate setting

Equally complex, and perhaps more controversial, are the rate setting methods employed across the demonstrations. Although still emerging during the initial stages of implementation, rate setting has now arrived at center stage, especially for the mature programs assessing the long-term possibilities of case management. Some program managers and providers assert rate setting will be the single most important issue in determining program viability.

Most demonstrations began operations with the goal of outperforming, i.e., having costs lower than, the existing fee-for-service equivalent costs for eligible care, generally on the order of 5 percent. Relying on consultants and other resources, the States arrived at actuarially determined costs of covered care for various rating categories, with some sites using as few as 2 categories (AFDC adults and AFDC children) and others use more than 70, as in Minnesota. These costs were then trended forward; adjusted for geographic differences; and deductions from costs were made for various reinsurance or slop-loss arrangements before final distribution of the costs to the appropriate program funds for provider disbursement. Some programs, such as Missouri, have established risk pools for special groups such as newborns with major medical problems; these programs have funded such groups with mandatory deductions from the capitation tales of all programs.

Even assuming a stable base, numerous complexities soon began to surface. They took on considerable importance given the tenuous nature of relationships with skeptical providers. Questions about the composition, homogeneity, and number of rating categories emerged, Trending factors were challenged. The use of local recipient experience rather than statewide experience was challenged, especially if the number of local Medicaid eligibles was small. Documentation to support the methodologies was also inadequate, inconsistent, or absent, The deductions made for funding reinsurance and stop-loss coverage, as well as the computation formulae used, have also been disputed in some demonstrations. Delays in getting rates approved at the State or Federal level occurred.

A more confounding problem arose when it became apparent that because of other program reforms and larger scale changes in health services, the fee-forservice base was not stable and evidently declining in a number of programs. Thus, when second year rates were computed some were found to be lower than first year rates; the differences were substantial amounts in some areas, such as New Jersey. Some observers contend that these pressures are just what are needed to compel PCCM's to manage even more effectively to justify the programs' existence; others are concerned that these pressures may have prevented the demonstrations from being able to test adequately the strategies being implemented. In either case, this issue has the potential to inhibit severely physician recruitment and to destabilize provider relations and participation. Consequently, intensive discussions and negotiations to address this program are under way in a number of program sites. Within the evaluation of the demonstrations, the rate setting methodologies and processes are being extensively reviewed.

Management information systems

The severe management information system (MIS) problems of the first year are being solved at most of the program sites. For some programs, this has meant refinement and redesign, establishing supplemental systems or replacing contractors who failed to produce usable systems on a timely basis. Despite this progress, problems are still apparent; they are exacerbated by growing provider interest in more sophisticated systems, which will enhance providers' ability to carry out their responsibilities in the demonstration programs.

It is important to note that while having an MIS is not an assurance of an effective program, its absence has profound negative consequences in such areas as the following:

- Program operation and assessment.
- Eligibility and enrollment linkages.
- Provider participation and payment.
- Financial monitoring.
- Utilization review and management.
- Quality assurance.

In addition to having system components to support each of these areas, the coordination and report generation from them must be precise and timely to facilitate such activities as prior authorization of specialty services or preadmission certification, which some plans and PCCM's are implementing.

The interrelationship between incentives and provider behavior becomes apparent when looking at such areas as utilization monitoring. Where plans and case managers are at financial risk for specialty care, they wish to be positioned to be aware of and, perhaps deny, unauthorized out-of-plan care. When such problems appear extensive or persistent, the PCCM may then implement more stringent authorization measures. In Missouri, plans have had to decide whether to reimburse other providers for unauthorized out-of-plan use. In some cases these other providers may be competing prepaid health plans that are well aware of the demonstration program and its lock-in provisions for enrollees. When MIS reports are unavailable or unusable, it is not possible to monitor care closely. For example, the reports of specialty use in one program given to the PCCM list the specialist only by Medicaid provider number rather than by name; this makes it difficult for the PCCM to identify and resolve unauthorized use problems.

Quality assurance

The second year of demonstration programs has witnessed increased attention to quality assurance as well as utilization review. For a program using prepayment and limitations on choice of provider, and an overarching goal of cost containment, concern about under-utilization is generally regarded as the principal quality of care concern. Stated differently, the service use to be reduced by the demonstration programs is intended to be only unnecessary care. Because of this focus, much of what has been cited as quality assurance activities are largely utilization review issues.

However, some more typically quality assurance activities are now occurring at various demonstration sites:

- Employment of clinical personnel at the State or risk-assuming intermediary tiers to oversee or conduct quality assurance efforts.
- Monitoring of 24 hour availability of the PCCM.
- On-site medical record audits.
- Operationalizing of quality assurance plans and committees by providers.
- Small stale treatment outcome or sentinel event studies across providers.
- Development of clinical management protocols for selected high prevalence conditions.

Notwithstanding these examples, the programs uniformly cite quality assurance as an area to which they will devote additional attention and resources in the next year.

Managerial concerns

The final issue which incorporates many elements of those presented earlier, is program management. These programs have severely tested the developing agencies' abilities. Agencies have had to take programs from conceptualization to full implementation in highly compressed time periods. Because most Medicaid agencies have neither the organizational slack nor many of the requisite technical skills in-house, reliance on outside consultants has been extensive. At best, this added another layer of administrative complexity and, at worst, it has provided the basis for serious conflict, especially when consultant nonperformance has become an issue.

A core group of committed staff has proven critical in certain program sites. Other program sites have experienced substantial turnover but have still been successful, suggesting that factors beyond permanency of personnel play a role. The tensions between delegating and centralizing functions, as noted in New Jersey and elsewhere, have also been played out differently, assuming that some minimum, adequate number of personnel are engaged in the key program operations. Provider perceptions are also important. Providers have reported how disconcerting it can be to have to deal with a stream of unfamiliar and continually changing personnel.

The evidence on the advantages and disadvantages of the risk-assuming intermediary tier versus direct contracting between the State and prepaid health plans and providers is mixed and inconclusive. The risk-assuming intermediary can link and tailor a program to a local market, but it also adds another party to the complex round of negotiations required to get a demonstration program started. In addition, as some critics suggest for Monterey, the strained State-Initiative relationship may be a contributing factor in the ultimate demise of a program. For New York, some have questioned the role of MediCap when only a single provider network is participating. Given this situation, MediCap's position would seem to be duplicative, at least until other plans are recruited.

Key issues emerging in year three

As previously noted, the continuing programs remain at various points of development and maturation as many enter what is expected to be the final year for them, unless extensions are granted. A number of important developments are expected:

- Transition to permanent status for certain programs.
- Continued transformations in local health service markets.
- Increased evidence of competition among providers for enrollees.
- Rate setting to become more contentious.
- Quality assurance programs to become more prevalent and stringent.
- Case management to be better understood by providers and enrollees.
- Appropriateness of case management to be challenged for selected eligibles.

These issues are now briefly described.

Transition—Santa Barbara, Missouri, and New Jersey have requested waivers (section 1915b) from HCFA to continue their demonstration programs when the demonstration funding expires in 1986. Such waivers are required because a number of program features represent exceptions to conventional Medicaid program requirements and thus must be specifically exempted by the waiver process. The Santa Barbara and Missouri programs are likely to be approved. Few significant changes are expected because both report that their own cost analyses suggest positive financial results, a requirement for granting the waiver. As discussed previously, rate setting will be an issue of major importance in both of the programs. In California, it will be an issue because of the shrinking fee-for-service base and the administrative cost dispute with the Stale; in Missouri, it will be an issue because of the program's expressed interest in going to provider-specific captation rates. More competition is expected among providers if rate setting is perceived as satisfactory. The New Jersey waiver request is currently under review.

Transformations in local health service markets—As hospital occupancies continue to decline, alternative delivery system enrollment will continue to grow, and competition will grow more fierce. The capitated demonstrations are likely to receive at least indirect support from these larger market forces, especially as fee-for-service payment becomes the exception rather than the rule, as it appears to have in such places as Minneapolis. To a limited extent, the demonstrations have stimulated interest in prepayment among providers, like the neighborhood health centers in Missouri; the demonstrations have given providers much needed experience with prepayment. Despite these changes, it is not yet clear if program designs or recruitment strategies will succeed in bringing more previously non-Medicaid providers into participation. These strategies may simply convert traditional providers to prepayment.

Competition among providers for enrollees—Even if few additional providers enter the demonstrations or their successor programs, it is expected that where the program proves creditable and feasible, economies of scale will be pursued. It will be of interest to see if, given the nature of the mandatory basic service coverage of the programs, some providers attempt to add optional services to attract enrollees. Another alternative would be more intensive media-related publicity efforts, which have not proven particularly effective in affecting initial plan/provider choice. This competition also presumes the maintenance of capitation and other rates that arc acceptable.

Rate serving conflicts—In order to assure provider participation the programs are required to pay rates that are perceived by providers as adequate. Florida's demonstration was unable to recruit prepaid health plans because it offered rates discounted from what were already among the lowest Medicaid fee-for-service rates in the country. This is one of the principal lessons of the Florida demonstration failure.

For program managers and providers, the negotiation and retention of adequate races is likely to be a source of severe conflict, especially if the program has proved to be feasible and profitable. The issue of adequate rates has significant political and equity overtones, as well as technical ones. These overtones suggest that easy solutions will nut be found despite the clear aim of cost containment.

Quality assurance—For programs that have demonstrated that they can be implemented and cost savings can be achieved, the next questions which inevitably arise are how were the savings attained and what may have been given up. This issue is likely to intensify interest in finding out if the reductions in service cost, use, or substitution effects of less expensive for more expensive care, have had adverse health consequences.

Understanding case management—Despite assertions by many primary care providers that they have always been case managers, the embodiments of case management found in many of the demonstration programs has taken time to learn and understandboth for providers and enrollees. This is important to note for two reasons: first, learning effects are more likely to be apparent in provider and Medicaid recipient behavior as more as time passes; and, second, gaming of the system is likely to increase as sophistication grows. This latter point may apply both to the recipient who realizes that the emergency room is unlikely to turn away an insistent but unauthorized patient, and to the provider who may try to encourage high-risk individuals to enroll elsewhere. The key issue is that case management, like prepayment enrollment, provides an acculturation experience that will take time to absorb.

Appropriateness of case management—Some evidence has already emerged that primary care case management may be inappropriate for certain patients with long-standing provider relationships for chronic conditions. To the extent these providers are not candidates for becoming primary care case managers, disruptions and discontinuity may result. These patients and others with pre-existing conditions also present problems of adverse selection for providers

with whom they do enroll, sometimes requiring setting up complicated risk pools for such circumstances. It is likely that other programs, particularly those that cover the disabled populations as well as AFDC and SSI eligibles, will exempt these patients from the conventional case-management program, as has been done in Monroe County, or will devise some alternative program for them.

Conclusion

Significant progress occurred in most of the demonstration sites during this period of time. The problems addressed by most programs have been ones of development and implementation rather than of design and consensus building which marked the first year. Much more has been learned about the feasibility and difficulty of making these programs work; in two cases (Santa Barbara and Missouri) it has become apparent that the programs will continue after the demonstration has been concluded. However, the answers to many other questions are inconclusive, and the long-term fate of the other programs, including their cost-containment strategies, are still unknown.

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8. Remaining Issues:

- Transition to permanent status for certain programs.
- Continued transformations in local health service markets.
- Increased evidence of competition.
- Rate setting conflicts.
- Quality assurance stringency.
- Understanding case management.
- Appropriateness of case managers.
- 9. Conclusion: Significant progress has been made.

The Santa Barbara and Missouri programs will continue after the demonstration project concludes.

CW/amc

Enclosure